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The effects of chronic childhood illness on healthy siblings.

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THE EFFECTS OF CHRONIC CHILDHOOD ILLNESS ON HEALTHY SIBLINGS

A Dissertation Presented

By

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DEDICATION

To my siblings

Richard, Kenneth, Jean

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ABSTRACT

The Effects of Chronic Childhood Illness on Healthy Siblings

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Although evidence suggests that long term illness in a child is a significant stress on family members, few studies of family adaptation to childhood illness have assessed how ill children's healthy siblings understand and respond to this unique life stress. The present study investigated whether the experience of living with a chronically ill sibling was related to young adults' beliefs regarding locus of control of health, perceptions of vulnerability to illness, and attributions concerning causes and prevention of illness. Twenty-seven experimental and 27 control subjects were assessed with the Multidimensional Health Locus of Control Scale, Likelihood of Illness Scale, Vulnerability to Illness Questionnaire, and the Concept of Illness Task. In addition, experimental subjects were assessed with descriptive measures regarding their retrospective and current perceptions of the impact of chronic sibling illness on their lives. Results of both quantitative and qualitative data analyses indicated that living with a chronically ill sibling during childhood has

a powerful effect on young adults' conceptualizations of illness and goals for the future. Healthy siblings of chronically ill children demonstrated a stronger belief in chance determining health and illness than did matched individuals who had not lived with an ill sibling. The experience of living with an ill sibling was also associated with young adults' beliefs in the prevalence of illness in the general population as well as with differential attributions for the causes and prevention of illness. In addition, the experience of caring for an ill sibling was associated with choosing majors in college which would prepare young adults for "helping" professions. These findings were discussed in relation to previous research by the author examining latency age siblings' responses to childhood illness. A comparison of both studies revealed the specific burdens that chronic illness places on family members as well as a complex interplay of adaptive strategies utilized by the well sibling and the family. Implications of findings on the developmental changes in well siblings' response to chronic childhood illness were discussed in regard to future research and intervention.

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Introduction

This nation's number one health problem, for both children and adults, is chronic illness (Gortmaker & Sappenfield, 1984). Seven to ten percent of all children have one or more serious chronic illnesses of physical origins (Gortmaker & Sappenfield, 1984; Travis, 1976). The percentage of ill children with chronic illness has increased in recent years, in part because medical advances have changed many once fatal childhood illnesses to more long-term, chronic conditions. Thus, more families are now living with chronically ill children and for longer periods of time.

Long term illness in a child is a significant stress on family members: they must cope with the physical, financial, and psychological hardships of living with an ill child (Drotar, 1978). For progressive illnesses, the family must watch the sick child slowly decline in health. Even if the child lives a relatively normal life span (with impaired physical functioning), the family may have to continually readjust to periods of acute exacerbations alternating with remissions (Mattson, 1972). As Koocher (1983) has noted, "these new survival statistics have generated a whole host of psychological stress issues. Not the least of these is the matter of long term uncertainty

and the stresses of the chronic helplessness this induces" (p. 1276).

There is a considerable body of literature on the psychological and emotional impact of illness on the family (see for example, Boyle, Di Sant'Agnese, & Sack, 1976; Debuskey, 1970; Drotar, 1977; Futterman, & Hoffman, 1973; Gamstorp, 1980; Green & Solnit, 1964; Green, 1967; Hughes, 1976; Kupst & Schulman, 1980; Melamed, Meyer, Gee, & Soute, 1976; Miller, 1979; Nager, 1978; Neil, 1970; Seigel, 1976; Sigler, 1970; Solnit & Stark, 1961; Sperling, 1978; Steinhauer, Muchin, & Rae-Grant, 1974). For the most part, however, these studies of family adaptation have focussed on parental and patient responses to living with the illness. Few investigators have explored how healthy siblings understand and respond to this unique life stress--how the extreme focus of concern on one child's illness affects well children's perceptions of themselves, and their own health, their family relationships. It may be that these children's feelings parallel those of their parents in many ways, "but children stand in a different relationship to the family and to the disability" (Featherstone, 1981, p. 141).

As family systems theories have pointed out, stress on one part of the family will affect all members in the family and will cause shifts in the organization and behavior of the family (Minuchin, 1974). Yet sibling interaction and responses to stress are an often overlooked part of family

functioning (Bank & Kahn, 1975). Thus, although a survey of life events indicated that sibling illness was among the most stressful of 42 life events for children (Coddington, 1972), siblings of chronically ill children are often the most neglected members of the family during treatment (McKeever, 1983; Patterson, Denning, & Kutscher, 1973). It has been argued as well that the ill child's emotional development and adjustment to his/her illness "depends more on the way in which the parents and family related to the child than to the extent of the handicap itself" (Bentovim, 1972), and that healthy children's responses to sibling illness potentially influence the course of the illness (Allan, Townely, & Phelen, 1974; McKeever, 1983).

This chapter will begin with a review of the literature regarding healthy children's response to sibling illness. Research in this area has primarily focussed on the psychosocial adaptation of well siblings. For the purpose of clarity, the research and clinical reports have been classified into categories based on the method of inquiry. An underlying theme throughout the literature is the notion that well siblings' theories about illness and its impact on the family strongly influence their behavioral adaptation to the stress of living with a chronically ill child. However, as well be discussed, the lack of uniform findings and the methodological limitations of many of the research designs

limits the conclusions that can be drawn from this previous research.

In light of the above concerns, the theoretical basis for the present study--an investigation of young adults' response to sibling illness--will then be presented. It will be argued that an understanding of how healthy siblings' beliefs about illness develop and change over time will enhance our understanding of response to sibling illness. Social psychological formulations regarding reactions to misfortune as well as the health locus of control construct will then be presented in an effort to provide theoretical support for the idea that living with an ill sibling can affect well siblings' theories about the world and about their own vulnerability to illness. The meaning that the individual attaches to sibling illness is influenced by family response to illness. Therefore, the importance of family communication patterns in mediating the stress of living with a chronically ill sibling will be briefly described. The chapter will conclude with a discussion of the specific questions in the present investigation.

Research on Healthy Siblings of Chronically Ill Children

The research and clinical literature on siblings of chronically ill children can be classified into four categories, based on method of inquiry. One category,

Clinical Reports, provides observations and clinical impressions which have emerged from clinicians' work with ill children's families. A second category, Parental Reports, is comprised of parental reports of siblings' problems in coping with the illness; these reports often include some data obtained through incidental findings in family studies. The third category, Interviews with the Child, presents semi-structured interviews with the healthy siblings of ill children. Finally, the category Projective and Objective Assessments of the Child, provides studies where a variety of projective and objective psychological tests have been administered to assess children's understanding of their families' situation.

The methodologies of these studies are quite different. Some studies use research instruments designed solely for the study. Others use standard tests but do not provide full discussions of results or methods of scoring. There is a wide age range of children within and across studies, and few studies include control groups of healthy siblings of <u>healthy</u> children. As a result, it is difficult to make comparisons across different studies, and conclusions drawn across studies must be guarded. Nonetheless, a review of this work does suggest several hypotheses which warrant continued refinement and study.

Clinical Reports

These uncontrolled observational studies were not designed to collect data for the purpose of testing specific hypotheses. They are observations and theoretical discussions of the family's experience in living with a chronically ill child, derived through clinical experiences with this population. In these reports, often the distinctions between observations and inferences about these observations is unclear. Given that these observations are generally made on a biased sample of children (i.e., children currently in treatment for emotional and behavioral difficulties), it is not surprising that the reports tend also to be "long on stress and short on coping" (Hamburg, 1974), emphasizing the disruptive and negative aspects of children's reactions to this stress. Nevertheless, these studies are valuable both for their descriptions of how a child's illness can affect family activities, and for their intriguing hypotheses about the siblings' emotional and behavioral responses to chronic childhood illness.

According to these reports, most chronic illnesses have the effect of changing family routines and activities, increasing the level of tension and anxiety in the home, and focussing parental attention and concern on one child (Burton, 1975; Travis, 1976). For example, siblings of children with congenital heart disease or cystic fibrosis may be prohibited from activities with crowds because of

parental fears that infections will be introduced into the household and jeopardize the life of the sick child. (McCollum & Gibson, 1970; Travis, 1976). Siblings of children with muscular dystrophy are often burdened by helping with physical care and "some dystrophic children would enslave their physically normal siblings, 'hand me this, pick up that'--if not restrained" (Travis, 1976, p. 423).

The families of children with cystic fibrosis are extremely involved in the medical management of the ill child: administering numerous medications, and carrying out extensive physical therapy, often twice daily (Drotar, 1978). The social activities of family members are often limited because of the ill child's chronic productive cough (Rosenstein, 1970). Families of diabetic children must master insulin injections, evaluations of urine testing, and must become familiar with new dietary and meal planning requirements. "Time must be re-ordered to include these new tasks in conjunction with increased scrutiny of food intake and urination" (Sargent, 1982). Children with cystic fibrosis, diabetes, asthma, hemophilia and leukemia often require emergency hospitalization which increases family anxiety and disrupts family functioning (Debuskey, 1970). It appears that in any chronic illness, family activities are likely to be reduced due to fear of a developing crisis, potential distance from medical care, lack of funds, time,

and energy, and inability of the ill child to endure normal activities (Kruger, 1980).

Emotional responses of siblings. Clinicians have reported that in response to these changes, many siblings harbor feelings of resentment, anger and guilt. Well siblings are found to be quite jealous of the parental affection and attention given to their ill siblings, and resentful of the patients' escape from disciplinary measures (Burton, 1975; Featherstone, 1981; Sourkes, 1980; Travis, 1976). Moreover, the usual competitive feelings between siblings are affected by illness markedly: upon illness onset, rivalries from the time of the sick child's birth are often reactivated if the sibling is older than the patient (Burton, 1975).

Although well siblings may feel quite angry about being deprived of their share of parental resources (time, money, affection, attention), often these siblings are unable or unwilling to directly express their anger toward the seriously ill child. Similarly, anger at the parents, perhaps for not protecting the patient from illness, is often present; these feelings, too, may not be expressed, however, partly because they involve feelings of insecurity regarding the parents' ability to protect the well sibling from similar problems (Sourkes, 1980).

Well siblings often feel guilty about being healthy and therefore able to participate in activities which the ill child cannot. Guilt feelings may also arise from the well

child's belief that s/he has caused the illness or made it worse. Sourkes (1980), in her study of siblings or children with leukemia, found that many sibling views on what causes illness include implicit or explicit self references. Siblings often perceive the anger and resentment they express (or simply feel) during the patient's remission as causing subsequent exacerbations in the illness (Binger, 1973). Share (1972) and Heffron (1973) report that siblings can become overwhelmed by guilt and fear during a patient's hospitalization, especially if they had expressed anger toward the ill child when in remission.

Problems are posed as well by the world of classmates and strangers: the well sibling is often embarrassed and confused by his/her "different" family (Featherstone, 1981). These feelings often come at a time when children are very concerned about looking "normal." The unthinking, but often cruel, reactions of classmates or adult strangers to the ill sibling can make the healthy child feel both ashamed and angry for his/her identification with the ill child.

> They stand with one foot in the world of normal classmates and the other in their exceptional family. . . . Forced to mediate, to explain, and sometimes to choose between conflicting loyalties, brothers and sisters can end up angry at the normal world, the disabled child, and themselves. (Featherstone, 1981, p. 142)

These children may feel not only lonely and isolated from their peers who have "normal" families, but also lonely

and isolated within their own families, as they deal with a number of losses. They lose physical and emotional attention from their parents. Moreover, they observe the sick child getting special parental treatment. As a result, they often view parental preoccupation with the sick child as a rejection of themselves (Burton, 1975; Lindsay & MacCarthy, 1974; Sourkes, 1980). These children often lose the reciprocal support and companionship that siblings can provide one another. As Featherstone (1981) has pointed out, the healthy child in small families "sometimes endures a particularly poignant sort of loneliness, a longing for a 'real' brother or sister with whom they might share more, one who could reflect their own feelings and experiences" (p. 144). If the well child is aware that the illness is fatal, then s/he must come to terms with a greater loss: the impending death of a brother or sister. Intense feelings of depression and anxiety in anticipation of the death may develop as part of the mourning process (Lindsay & MacCarthy, 1974).

Confusion and anxiety about the causes and course of the sick child's illness can increase the well child's sense of isolation. Parents often avoid discussion of the illness with their healthy children, perhaps hoping to avoid burdening them with sadness and loss (Featherstone, 1981). Unfortunately, this silence can result in the child's

feeling even more alone with his/her anxieties, and his/her negative feelings.

Behavioral Reactions of Siblings. These clinically observed feelings of anger, depression, confusion, and loneliness can lead to disturbances in behavior. Rosenstein (1970) speaks of a high incidence of behavior problems in the siblings of children with cystic fibrosis. These siblings exhibit "resentment, depression or acting out behavior, with little evidence of overt hostility" (Rosenstein, 1970, p. 29). Behavior disturbances can also take the form of regression, where the sibling seems to retreat to earlier behavior patterns while trying to cope with heightened anxiety (Lindsay & MacCarthy, 1974). Some children act out, perhaps as a defense against depression, while others withdraw into daydreams and obsessive, anxious thinking (Sourkes, 1980). In order to disrupt the parent's preoccupation with the ill child, healthy siblings may exhibit a range of attention-seeking behaviors, including clinging, tantrumming, and stealing (Kew, 1975).

A number of authors (Gyulay, 1975; Lindsay & MacCarthy, 1974; Sourkes, 1980; Travis, 1976) find that well siblings often exhibit psychosomatic symptoms, sleep problems, and accident proneness. These authors hypothesize that these reactions may be due to the well sibling's <u>wish to be ill</u>, and thereby gain parental attention and nurturance. However, they also argue that it may reflect the sibling's

preoccupation with the sick child, resulting in an identification with his/her illness.

In summary, the Clinical Reports describe how stresses imposed by the need to care for a chronically ill child affect family activities, thereby increasing the level of anxiety in the home, and focussing parental attention and concern on one child. According to these clinical observers well siblings harbor feelings of resentment, anger, and guilt, which can lead to a range of disturbances in behavior.

Parental Reports

Interviews. The first group of reports reviewed in this section used semi-structured interviews with parents to assess siblings' adaptations to illness. As will become clear, the general finding from using this approach has substantiated the claim of serious emotional impact on the well child. Although some parents seem to perceive positive effects of the illness (noting increased nurturing, compassion and cooperation in healthy siblings), most report significant problems in healthy siblings, particularly the child closest in age to the sick child (Allan, et al., 1974; Binger, 1969, 1973; Burton, 1975; Hunt, 1973; Kruger, 1980; Taylor, 1980a; Turk, 1964). However, none of these studies included either comparison groups of siblings of healthy children or objective methods to assess siblings' response to the ill child. Thus, the "increased disturbance" noted

could be an artifact of having inappropriate expectations of normative disturbance levels or using subjective interviews as criterion measures. Sourkes (1980), in fact, has discussed how parental emphasis on disturbance rather than coping in siblings may distort parental reports.

> Ongoing parental reports may be biased in perceiving siblings as "problems" in contrast to the idealized patient. Furthermore, the parents' tolerance threshold will be lower under stress, and thus "symptomatic" behavior on the part of the siblings will be acutely salient (Sourkes, 1980, p. 53).

Mothers of children with cystic fibrosis report that well siblings have problems of soiling, stealing, fire-lighting, undiagnosed recurring abdominal pain (Allan, 1974); playing sick to get attention; feeding and sleeping problems; and nervousness (Kruger, 1980; Turk, 1964). Interviews with parents and teachers of siblings of children with myelomeningocele reveal problems of increased anxiety, resentment, and feelings of rejection and neglect (Hunt, 1973).

Burton (1975), who contacted all known families of children with cystic fibrosis in Northern Ireland, asked parents about the effects of this illness on the behavior and attitudes of well children in the home. Almost half of the older siblings displayed positive protective feelings toward the sick child and were less aggressive than before the illness, giving in more easily to the sick child. Anxiety about the illness and feelings of responsibility of

the sick child's well-being were common. Jealousy was rarely apparent in older children, which Burton theorizes may be due to the older child's ability to hide negative feelings: older child's guilt and worry concerning the sick child "may limit open expression of less acceptable behaviors" (Burton, 1975, p. 196). Problem behaviors exhibited by these well siblings included bedwetting, school difficulties, and accident proneness.

Parents of children with leukemia were interviewed in Binger's (1969; 1973) study regarding the long- and short-term effects of the illness on the family. Binger (1969; 1973) reported that up to 50 percent of the siblings of children with leukemia showed behavior patterns indicating difficulty in coping.

> Problems described by parents, included an onset of severe enuresis, headaches, poor school performance, school phobia, depression, severe separation anxiety, and persistent abdominal pains. (Binger, 1969, p. 416)

They also found, as have independent observers cited earlier, that well siblings tend to interpret the parent's preoccupation with the sick child as a rejection of themselves.

Studies of group discussions with families of children with leukemia indicate similar difficulties with intensified sibling rivalry, guilt, and behavior problems (Heffron, Bonnelaere, & Masters, 1973). However, they also found that these problems diminished greatly when the siblings were

given the truth about the diagnosis and course of treatment and were encouraged to discuss openly their feelings about the ill child.

Questionnaires. Several studies have used parental questionnaires and behavioral checklists to assess sibling adjustment. While this methodology is more standardized than parental interviews, it does not provide as rich a source of qualitative and descriptive data. It is important to also recognize that these reports are assessments of parental perceptions of the child's adjustment. As noted earlier, parental emphasis on disturbance rather than coping in siblings may distort parental reports.

Lavigne and Ryan (1979) asked parents of children in hematology, cardiology, and plastic surgery clinics to complete the Louisville Behavioral Checklist (no reference given in the Lavigne & Ryan report), for their healthy children. The same questionnaire was also administered to parents of siblings of healthy children. They found that siblings of the ill children were reported to be significantly more withdrawn and irritable than were siblings of healthy children. Tew and Lawrence (1973) report similar results when parents and teachers completed the Bristol Adjustment Guide (Stott, 1973) for the siblings of children with spina bifida. These siblings were almost four times as likely to show signs of maladjustment in school than were siblings of healthy controls.

Mothers completed the Psychiatric screening Inventory (Langer, et al., 1976) for their well children in a comprehensive and well controlled study of 239 families of children with cystic fibrosis, myelodysplasia, multiple handicaps, and cerebral palsy (Breslau, Weitzman, & Messenger, 1981). It was found that the proportion of siblings with serious psychological impairment was not significantly different from the proportion of impaired children in the control group of healthy siblings of healthy children. There were intensity differences, however, so that the siblings of ill children scored significantly higher on the mentation problems, fighting and delinquency subscales.

A study by Gath (1972) also seems to contradict earlier studies that reported increased disturbance in siblings of ill children. Parents and teachers completed behavioral scales designed by Rutter, Crutter, Tizard, and Whitmore (1970), which discriminate between children attending child guidance clinics and other children in the general population. No difference in the frequencies of behavior problems were found among the three groups in the study: siblings of children with Down's syndrome, siblings of children with surgically repaired cleft palates, and siblings of healthy children.

In summary, both the parental interviews and parental questionnaires generally seem to substantiate the emotional

impact of sibling illness on the well child that clinicians have reported. However, not all siblings are thought to develop lasting psychological difficulties. And in fact, Lavigne and Burns (1981) claim that "most do not, and there are even signs of emotional growth in some instances" (p. 349).

Interviews with the Well Sibling

Three studies have been reported using semi-structured interviews to assess the impact of chronic childhood illness on their healthy siblings' lives (Gogan, Koocher, Foster, & O'Malley, 1977; Gogan & Slavin, 1980; Taylor, 1980a). However, none of these studies has used comparison groups of healthy children with healthy siblings. It is unclear, therefore, to what extent these children's attitudes actually reflect the stress of living with a chronically ill sibling, apart from other sibling factors.

Retrospective interviews with siblings of former cancer patients revealed emotional concerns such as feeling jealous, resentful, abandoned, and fearful of their own health (Gogan, et al., 1977; Gogan & Slavin, 1980). Feelings of guilt were quite common; according to the authors, these feelings appeared to be directly related to the lack of information about and poor understanding of the patient's illness. Importantly, siblings also reported some positive aspects of the illness experience as well,

including increased closeness to family members and enhanced personal emotional growth.

Taylor (1980a) interviewed twenty-five healthy school-aged siblings of children with asthma, cystic fibrosis, and congenital heart disease. She was interested in their relations with family members, knowledge of siblings' condition, and feelings about themselves. Children's statements revealed that they experienced feelings of deprivation in regard to parental time and attention, including physical care, recreational activities, and material items. "Lack of touch and physical closeness were predominant deprivations noted by the well children" (Taylor, 1980a, p. 114).

Feelings of inferiority were also expressed and seemed related to lack of feedback from parents: "several well siblings stated that they could never do anything good enough to get the parents' attention or earn status similar to the ill children" (Taylor, 1980a, p. 114). The largest single effect of the illness upon the well siblings was manifested by feelings of isolation.

> Many children described feelings of being alone or outside the family relationships. They saw the parents and ill children as dyads which excluded them. . . . They reported feeling peripheral to the family on [medical] clinic visits and generally ignored by health care providers. (Taylor, 1980a, p. 113)

As was true in the work of Gogan and her colleagues (Gogan, et al., 1977; Gogan & Slavin, 1980), Taylor's

(1980a) study reported positive effects from living with a sick sibling, particularly when the well child was responsible for some of the treatments of the child. Taylor believes that some of the well children's statements indicated increased empathy toward the ill child and "a sensitive perception of how the parental relationship was affected by the illness" (Taylor, 1980a, p. 115).

The Taylor (1980a) study also refers to importance of siblings' conceptualizations about illness as a variable influencing their response to illness. According to Taylor, well siblings often do not understand either the cause of the illness or why the ill child behaves the way s/he does. Taylor argues that this lack of understanding is directly related to the children's fears about developing the illness themselves. She suggests that this fear of developing illness often results from the well sibling's concerns about wrongdoing: feelings of guilt about thoughts and about behavior toward the ill sibling were quite pervasive.

Projective and Objective Assessments of the Well Sibling

Studies which directly assess the well sibling through projective or objective techniques generally tend to compare healthy siblings of ill children with the ill children rather than with healthy siblings of healthy children. However, the results of these studies are quite informative; in general, they suggest that well children show equal if

not greater stress than do their ill siblings (Cairns, Clark, Smith, & Lansky, 1979; Siegel & Kornfield, 1980).

Siegel and Kornfield (1980) used the Kinetic Family Drawing Test (Burns & Kaufman, 1972) to evaluate attitudes and conflicts in both children with muscular dystrophy and their normal siblings. Children in both groups were asked to draw a picture of everyone in their family doing something. The most significant characteristic of the well siblings' drawings was that they "encapsulated" themselves in the pictures, removing themselves from their handicapped siblings. The authors hypothesized that this encapsulation reflected the well child's feelings of isolation as well as fears of hurting the patient, an interpretation supported by Taylor's (1980a) work.

Siegel and Kornfield (1980) reported that the drawings also indicated intense anger and depression, and did so in ways which would not have been easily identified in clinical interviews alone. Moreover, they also reported that well children's drawings revealed feelings of conflict about competition with their ill siblings, especially in regard to maternal attention.

Crain, Sussman, and Weil (1980), using both direct observations of mother-child interaction as well as parental questionnaires, found that the major difference between diabetics and their healthy siblings was that the diabetic child had a closer expressive relationship with the mother.

The California Tests of Social Maturity and Achievement (Tiegs, 1957), Coopersmith's Measure of Self Esteem (Coopersmith, 1959), and Farber's Self-Satisfaction Form (Farber & McHale, 1959), used to assess children's behavioral and emotional statuses, yielded no statistically significant difference between the two groups.

Similarly, no significant differences were found between 23 children with cystic fibrosis and their 26 healthy siblings on the Piers-Harris Self-Concept Scale (Piers, 1969) or the Missouri Children's Picture Series (Sines, Pauker & 1971). In fact, the average total Piers-Harris self-concept score for the siblings included in this study was higher than that reported in other studies for normal children. The authors provide only a limited description of the information obtained from the Missouri Children's Picture Series, unfortunately, noting only that group profiles for both groups are within "normal" limits; whether more refined analyses would yield group differences cannot be determined from their report.

Contrary to their results, Cairns, et al. (1979) found that siblings of children with childhood cancer showed more distress than did the patients in several areas: (1) perceived social isolation; (2) perception of their parents as overindulgent and protective of the sick child; (3) fear of confronting family members with negative feelings, and (4) concern with failure. These findings were based on

assessment of patients and siblings utilizing the Bene Anthony Family Relations Test (Bene & Anthony, 1957) and the Thematic Apperception Test (Murray, 1943). Like other investigators, they found normal self concepts for both groups on the Piers-Harris self concept scale.

In summary, direct testing of children indicates that healthy children with ill siblings as compared to their ill siblings have normal self concept, but are troubled by feelings of isolation, depression, and unexpressed anger. No conclusions can be drawn as to how healthy children with ill siblings might compare to healthy children with healthy siblings on these measures.

Limitations of Previous Research on Siblings of Ill Children

Clinical reports and research, as have been documented in this review, have indicated that living with a chronically ill sibling, regardless of type of illness, has a profound impact on the lives of healthy children, placing them at risk for developing serious emotional difficulties. However, the literature also indicates that these effects are not uniform, and that many siblings do not show signs of maladjustment or emotional disturbance as a result of living with a chronically ill child. The factors which determine good versus poor adjustment are not clear. Researchers have therefore, examined a variety of demographic variables such as age, birth order, sex of sibling and of ill child, family

size, socioeconomic level, and the severity and type of sibling illness in order to determine the relationship of these variables to adjustment in siblings of ill children. Overall, the findings are contradictory and complex. Documentation of the relationship of sex of the well sibling to psychosocial adjustment includes reports of overall no effect (Breslau, Weitzman & Messenger, 1981), negative effects on brothers only (Lavigne & Ryan, 1979), and negative effects on sisters only (Farber, 1979; Tew & Laurence, 1975). Examination of the interaction of age, sex, and birth order also indicates contradictory findings. Lavigne and Ryan (1979) found increased pathology among younger sisters and older brothers of ill children while Breslau et al. (1981) found the opposite results: male siblings younger than the ill child and female siblings older than the ill child experienced higher rates of adjustment difficulties. With regard to size of sibship, McKeever (1983) notes in that while most investigators state that larger families provide healthier climates for siblings of ill children, this variable has not been researched systematically. No studies have investigated the effect of socioeconomic level on sibling response to illness.

It is also not possible to make a conclusive statement regarding the effect of severity or type of disease on sibling response; available research suggests that characteristics of the disease have no clear or consistent

effect on sibling reactions. Tew and Laurence (1975) reported that the relationship between severity of disease and sibling adjustment was nonlinear; Gath (1972) found no difference in the frequency of behavior problems among siblings of children in distinct illness groups; and Breslau, et al. (1981) reported that the type and severity of the child's illness or disability were not related to the psychological functioning of the siblings.

Unfortunately, much of the available literature on sibling response to childhood illness has serious methodological limitations. Most studies utilize idiosyncratic measures with poor procedural standardization. Moreover, methodologies across studies are not uniform, prohibiting direct comparisons. By far the most serious deficiency of the literature is the general lack of normal controls allowing comparisons between healthy siblings of chronically ill children and healthy siblings of well children.

In an effort to address the pervasive neglect of siblings in interventions for families of chronically ill children, many authors have described various therapeutic intervention techniques for ameliorating the psychological impact of chronic illness on well siblings (Azarnoff, 1984; Craft, 1979; Everson, 1977; Friedrich, 1977; Grave, 1974; Gyulay, 1975; Taylor, 1980b). However, until more well founded information has been gathered about the actual effects of childhood illness on well siblings, interventions

based on misconceptions can be harmfully misdirected. In fact, despite the suggestion that living with a chronically ill child places the well sibling at risk for developing emotional difficulties, researchers have not investigated the long term effects of sibling illness on the well sibling. In contrast to the number of studies examining problems of adjustment in childhood, there is a distinct lack of information regarding how the experience of living with a chronically ill sibling affects the lives of their healthy siblings in later years, when they have become young adults.

Theoretical Basis for the Present Study

An underlying theme throughout most of the literature reviewed on siblings of ill children is the notion that a sibling's emotional reaction to illness is strongly influenced by the beliefs s/he develops about the illness and the meaning that s/he attaches to the illness. As one example, clinicians have hypothesized that the prevalence of depression in siblings of ill children results from an increased sense of personal vulnerability, and a perceived lack of control over the external environment (Binger, 1979; Burton, 1975; Lindsay & MacCarthy, 1974; Taylor, Siegel & Kornfield, 1980). Children who live with a chronically ill sibling are continually confronted with evidence that "bad things" happen to innocent people; this experience with

injustice and uncontrollable events may have a profound impact on how they view themselves. Children in the studies reviewed often asked "why did this happen to our family?" "Did I have anything to do with my sister/brother getting sick?" "Will I get sick too?"

It is clear, then, from the preceding review, that well siblings' responses to illness can be understood in part by an examination of their perceptions of illness and their beliefs about the effects of illness on their lives. Interestingly, however, despite the wealth of evidence indicating that one's underlying beliefs about illness and perceptions of personal vulnerability influence adaptation to illness (Blos, 1978; Cohen & Lazarus, 1979; Hunt & MacLeod, 1979; Kirscht & Rosenstock, 1979, Willis, Elliot, & Jay, 1978), researchers have not empirically examined these constructs in siblings of chronically ill children.

In an effort to address this issue, Simons (1982) assessed assumptions and beliefs about illness in latency age siblings of chronically ill children. In contrast to most other research in the area of sibling response to illness, Simons' (1982) study was designed with controls, allowing comparisons between healthy children with ill siblings and healthy children with well siblings. Both quantitative and descriptive measures were included in this controlled observational design.

As was noted earlier, investigators have reported that children with chronically ill siblings are very concerned about their own health, frequently exhibiting psychosomatic symptoms (Allan, et al., 1974; Burton, 1975; Kruger, 1980; Lindsay & MacCarthy, 1974; Sourkes, 1980; Travis, 1976; Turk, 1964). The results of Simons's (1982) study indicate that siblings of ill children significantly more frequently than matched controls, viewed themselves as having been especially vulnerable to illness in the past, but expected that this vulnerability would decrease in the future. It appeared that this sense of decreased future vulnerability in the group of children with ill siblings might have been related to the well child's sensitivity to parental expectations; parents with ill children were more likely than were control group parents to expect a decrease in well siblings' future vulnerability to illness.

Previous researchers in this area have hypothesized that the well sibling's preoccupation with the ill child often results in anxiety regarding the cause of illness. Several investigators have noted that these children's views on what causes illness often include implicit or explicit self references, suggesting underlying beliefs that they have contributed to the occurrence of sibling illness (Sourkes, 1980; Taylor, 1980a). Simons' (1982) results indicated that healthy siblings were often preoccupied with the idea that they could avoid the fate of their chronically

ill sibling if they were "good" and "obeyed the rules." The group of children with ill siblings were significantly more likely than the comparison group of children to cite misbehavior as the cause of a child's hospitalization and to suggest changes in a child's behavior as the method of preventing future illness. This strategy of "being good and obeying the rules" also seemed to influence such children's behavioral adaptations to illness: clinical interviews indicated that caregiving behavior toward the ill child was prevalent, perhaps serving the defensive but adaptive function of differentiating the well child from their ill brother or sister.

Researchers examining healthy and hospitalized children's concepts of health and illness have shown that children's understandings of the causes and prevention of illness follows a cognitive developmental progression that parallels shifts in cognitive processes in general (Bibace & Walsh, 1978; Blos, 1978; Campbell, 1975; Nagy, 1951; Peters, 1978; Simeonson, Buckley & Monson, 1979). The findings of Simons (1982) suggest that living with a chronically ill sibling has a powerful impact on this process, affecting the latency age child's conceptualizations of illness. Carandang, Folkins, Hines and Steward (1979) provide further evidence of the intrusive role of sibling illness on well siblings' conceptualizations of illness. In their study, adolescents with ill siblings

demonstrated lower illness conceptualization levels than did adolescents with healthy siblings.

In summary, the way in which a well sibling responds to the stress of living with a chronically ill child seems to be related to his/her theories about illness and his/her beliefs about personal vulnerability to illness. As the research reviewed indicates, these theories and beliefs influence the well sibling's emotional and behavioral reactions to childhood illness. Social psychological literature investigating individuals' reactions to misfortune provide a theoretical perspective for understanding the development of well siblings' beliefs about illness and about personal vulnerability to illness.

Social Psychological Theory on Reactions to Misfortunes

Social psychological theory and research have identified cognitive and emotional processes that affect the way individuals perceive the world and explain events in their lives (e.g., Asch, 1952; Heider, 1944, 1958). Certain psychological formulations regarding victims' and observers' reactions to misfortune, especially have clear relevance to an understanding of response to sibling illness.

The following theoretical discussion rests on the notion that basic assumptions individuals hold about themselves and about the world are affected by the experience of victimization. Janoff-Bulman and Frieze (1983) has described two underlying assumptions affected by

victimization which appear directly related to the present focus. They are: (1) the assumption of invulnerability and (2) a belief in the world as meaningful.

Assumption of Invulnerability. Numerous researchers have found that people tend to overestimate the likelihood of experiencing positive outcomes in life, and to underestimate the likelihood of experiencing negative events (see, for example, Weinstein, 1980; Weinstein & Lachendro, 1980). Perloff (1983) has described this phenomenon as an "illusion of unique invulnerability" in people who have not been victims of serious misfortune. She describes this illusion as a belief that one is less vulnerable to victimization than are most other people. This tendency to underestimate's own personal vulnerability relative to other people's vulnerability was also demonstrated in a study by Lang-Gunn (1980). In her examination of college students' perceptions of the likelihood of becoming ill with specific diseases, she found that the majority of these young adults rated themselves as far less likely than the average person to develop any of a number of diseases.

A number of interrelated factors contribute to this perception of "unique invulnerability". Kirscht, Haefner, Kegeles, and Rosenstock (1966) found that subjects who view disease as very serious were most likely to perceive their own chances of contracting the disease as less than average. They argue that this perception is motivated by a

need to defend oneself against the anxiety-producing thought that one may be vulnerable to serious illness. Perloff (1983) suggests that the perception of unique invulnerability may also stem from a need for personal control, citing evidence that people generally have an exaggerated sense of their ablilities to control chance outcomes. "This illusion of control may lead people to overestimate their ability to obtain positive outcomes and avoid negative ones" (Perloff, 1983, p. 45). Perloff also notes that comparing oneself to others who are misfortunate contributes to the nonvictims' perceptions of unique invulnerability: "To the extent that we make downward comparisons, comparing ourselves to others who are less fortunate and more at risk than we are, we may be apt to see ourselves as uniquely invulnerable" (Perloff, 1983, p. 46).

According to Janoff-Bulman and Frieze (1983) and Perloff (1983), the experience of victimization "shatters" this assumption of invulnerability. As a result, the individual experiences an increased sense of personal vulnerability. Although much of the literature on victimization focussed on the victim's perceptions, Perloff notes that the knowledge that a family member or friend has been victimized by a negative event can heighten the observer's perceptions of his or her own vulnerability. She cites Janis (1974) in regard to this disturbing sense of vulnerability, who wrote:

> narrowly escaping from danger, losing close friends or relatives, and witnessing maimed bodies appears to have the effect of shattering the entire set of psychological defenses involved in maintaining expectations of personal invulnerability. (Janis, 1974, p. 162)

In sum, the experience of having a family member "victimized" by illness is likely to increase the individual's perception of his/her own vulnerability to a similar event. One can maintain the illusion that one is invulnerable to illness when there has been little direct experience with illness, but, as Perloff (1983) argues, "knowledge of victimized others may make it more difficult for individuals to deny their own vulnerability."

The belief that one is susceptible to potentially negative events and unprotected from danger can be especially anxiety provoking to the young child. Sourkes (1980), in her study of siblings of children with leukemia, states that sibling identification with the ill children often results in fears of becoming ill themselves.

> As children in the same family, past experiences that affected one child often affect the other. Thus it is only a matter of extension that an illness which could befall one child could just as easily befall another. This logic is especially true when the siblings cannot stipulate, either cognitively or emotionally, a cause for the illness. The apparent randomness of events leads the sibling to think: "why not me too?" (Sourkes, 1980, p. 62)

Simons (1982) found that siblings of ill children believed themselves to be especially vulnerable to illness in the past, but developed a perception of decreased

vulnerability to future illness. This perception, Simons (1982) argued, may have served the defensive but adaptive function of differentiation for the well child, signalling to the well child that s/he was not going to succumb to the sibling's fate. As Bank and Kahn (1981) have noted, in sibling relationships, each child is an object for conscious comparison and identification:

> Individually, each child pays close attention to the characteristics in oneself or one's siblings that the parents might find especially endearing. Silently but progressively, each struggles with whether he or she will become like a closely connected sibling, and thus solidifies a personal identity. (Bank & Kahn, 1981, p. 52).

As these children grow older, they may struggle to convince themselves that they are not like the ill child and therefore are not vulnerable to the unknown forces that attacked the ill child. Indeed, as the well child continued to live with the ill sibling over the years, it would become apparent that s/he was not going to likely to become chronically ill with the same affliction. Sibling response to illness, therefore, may be partly determined by this struggle to overcome a perception of increased vulnerability to illness.

The healthy young adult, who lived with a chronically ill sibling, may in fact perceive his/her own health as confirmation of personal invulnerability. Investigators have found that individuals who have experienced "near miss" situations often develop feelings of increased confidence

about their ability to avoid future negative outcomes (Janis, 1951; Wolfstein, 1957). The young adult sibling too may feel s/he has "escaped" the illness that afflicted the sibling.

Belief in a Meaningful World. Social psychologists have found that individuals are typically motivated to find a general purpose or pattern of meaning in the face of events which seem uncontrollable (Moos & Tsu, 1977). We "perceive our world as meaningful and impose meaning even in those instances where randomness may operate" (Janoff-Bulman & Lang-Gunn, 1984). In the specific case where a person is confronted with chronic illness, either in the self, sibling, child or parent, s/he tries to make sense of this event. It can be argued that for many of the children in the Simons (1982) study, the parents' explanation that sibling illness was due to chance did not satisfy the child's need for meaning. In the sibling's attempts to make sense of the world, the experience of illness, which seems both unpredictable and uncontrollable, needs to be explained. As Janoff-Bulman (1983) has pointed out, it is the selective incidence of victimization which is most difficult to explain. Simons (1982) reported that children with ill siblings often wondered about why their families were singled out, asking "why did this happen to my sister?" "Why did this happen to my family?" Or, "Why did this happen to my sister and not to me?"

Lerner (Lerner & Simmons, 1966; Lerner & Miller, 1978) has postulated a fundamental desire of the individual to believe in a just world "where people generally get what they deserve and deserve what they get" (Lerner & Miller, 1978). People will make interpretations of events in their lives in order to maintain this fundamental belief in a world as predictable and just. According to Lerner, "the person who sees suffering or misfortune will be motivated to believe that the unfortunate victim in some sense merited his fate" (Lerner & Simmons, 1966, p. 203). By convincing oneself that the victim was responsible for the illness and suffering, the observer can maintain a belief in a just world, where pain and suffering do not occur in a random way. A considerable amount of literature has shown that the most prevalent attribution for illness is blaming of the victim's behavior (Coates, Wortman, & Abbey, 1979; Lerner, 1980; Lerner & Miller, 1978; Walster, 1966). This type of attribution not only helps the individual make sense of the world, it may help the individual dismiss the heightened sense of personal vulnerability described earlier.

Indeed, as Simons (1982) found, latency age siblings of ill children tend to attribute the cause of illness to the behavior of an ill child. This attribution can be understood partly in the context of their earlier cognitive level: the younger child's cognitive construction of the world involves a strong respect for obedience to rules.

Piaget (1930; 1969) has described the child's thinking about concepts of justice as embracing a belief in "immanent justice". In the child's interpretation of the world, violations of the social rules are invariably punished, either by God or by some other natural force. The frequently documented just world beliefs in adults suggests that the child's experience of trying to make sense of sibling illness may make the expected shift away from immanent justice beliefs difficult.

A similar hypothesis regarding attributions about victims is presented by Walster (1966), who states that reactions to misfortune are motivated by a desire to view the negative event as a result of controllable factors. Rather than believe that such negative events happen by chance, the individual will blame the victim in order to maintain a belief that s/he will not become a victim.

> If we can categorize a serious accident as in some way the victim's fault, it is reassuring. We then simply need to assure ourselves that we are a different kind of person from the victim, or that we would behave differently under similar circumstances, and we feel protected from catastrophe. (Walster, 1966, p. 74)

In summary, the social psychological literature reviewed suggests that the experience of living with a chronically ill sibling has the potential of creating in well siblings a disturbing sense of personal vulnerability. Associated with this experience is a need to find meaning in the face of seemingly uncontrollable and unjust events.

Siblings' Reactions to Misfortune: A Unique Group

Researchers who have investigated reactions to victimization have focussed primarily on victims and unrelated observers in developing theories about perceptions of vulnerability. However, the sibling of a chronically ill child is in a unique position. S/he could be closely identified with the ill child and therefore perceive the self as "victim" and as more vulnerable to the illness than most people. Or, s/he could be differentiated from the ill child and therefore perceive the self as "observer" and not as vulnerable to the illness. The social psychological literature suggests that it is when observers indentify with victims in terms of perceived commonality of fate or situation that heightened feelings of vulnerability occur. As Lang-Gunn (1984) has pointed out, "the more likely observers perceive their own victimization to be, the more threatening the negative event, and the greater the motivation to preserve a belief in justice or controllability" (p. 25).

Although the development of well siblings' identification with ill siblings has not been directly addressed in the literature, research on sibling relationships in general has revealed a certain pattern to the process of identification and differentiation. Mosatche, Brady, and Noberini (1983) found that differentiation between one's self and one's sibling is

significantly higher during late elementary and high school years than it is at any other time before or after. Thus, one could argue that non-elementary school age siblings, living with the ill child and sharing many of the same experiences, feel closely identified with the ill sibling. A sense of vulnerability to illness may thus be enhanced. However, as they grow older and reach high school age, these children continually compare themselves to and differentiate themselves from the ill sibling. If this developmental process does, in fact, occur, the effect of this differentiation on their feelings of vulnerability to illness reamins unclear.

It is important to note that the theoretical formulations concerning reactions to misfortune have been developed on the basis of observing victims' and observers' reactions to distinct, unexpected and time limited negative events, such as accidents or rape, and with observers who are old enough to have developed assumptions about the world. This circumstance stands in contrast to a child who is born into a family with an ill sibling; such a child may have had no a priori assumptions about a meaningful and just world. Similarly, although the literature occasionally refers to chronic illness, or other prolonged aversive circumstances, the emphasis has been on initial reactions rather than long term responses to the experience of illness. Young adults who have lived with a chronically ill

sibling have observed the ill child's uncontrollable remissions and inexplicable changes in the course of the illness. Their attributions for illness are likely to be influenced not just by observing a sibling stricken by illness, but perhaps more importantly by the reality of living with an ill sibling over many years.

Indeed, as Lang-Gunn (1980) has noted, the reality of this sort of situation "would have to be severely distorted in an effort to maintain a belief in a just world via blaming the victim's characters or behavior". The young adult sibling's perceptions of vulnerability and attributions concerning illness may well be constrained, at least to some degree, by the reality of living with an ill child over a long period of time; this intimate knowledge of the course of illness must be incorporated into any satisfactory explanation of sibling response.

Health Locus of Control Beliefs

The preceding discussion of the illusion of perceived invulnerability and consequent attributions for illness focussed on the individual's motivation to establish a sense of safety from negative outcomes. Reference was made to the tendency to believe in a controllable world, where events do not occur at random or by chance. Although this tendency was discussed primarily in terms of perceived control over past, negative experiences, it is useful to investigate how living with an ill sibling might influence one's perception

of control over future experiences, particularly expectations of health and illness.

The locus of control construct (Rotter, 1966) has been useful in expanding our understanding of individuals' responses to health related events. Rotter (1966) originally developed the locus of control construct to describe the degree to which an individual perceives events that happen to him/her as dependent on his/her own behavior ("internal" locus of control) rather than luck, chance, fate, or powers beyond one's general control ("external" locus of control). According to Rotter (1966), general locus of control beliefs develop from specific experiences and past reinforcement histories; people who have experienced successful control attempts in the past will be more internal in their beliefs, while those who have experienced unsuccessful attempts at control will be more external.

In recent years, work on the locus of control construct has attempted to increase the predictive power of the concept by developing area-specific scales. One such scale of special relevance in the present context is the Multidimensional Health Locus of Control Scale (Wallston, Wallston, & DeVellis, 1978). This scale measures generalized expectancies in the health area and has been utilized in numerous studies to assess health control beliefs. (See, for example, DeVellis, DeVellis, Wallston & Wallston, 1980;

Germer & Price, 1981; Gossler, 1980; Hatz, 1978; Levin & Schultz, 1980; Pill, 1981.) Paralleling a general shift in personality research, there is currently much debate regarding whether such a scale measures relatively stable personality factors or expectancies that are situationally specific (Winefield, 1984).

Despite the large body of literature utilizing the Multidimensional Health Locus of Control Scale, few studies have examined potential determinants of health specific locus of control beliefs, particularly in terms of how experiences of illness in the family influence the development of those beliefs. The two studies which have investigated the relationship between early illness experiences and health beliefs suggest that health locus of control beliefs may in fact originate in relation to past illness experiences. Tolar (1978) found that women who had many childhood experiences with illness and accidents were more external than internal in their beliefs about the controllability of health. Lau (1982), utilizing a measure similar to the Multidimensional Health Locus of Control Scale, found that experiencing many illnesses in one's family was positively related to a belief in "chance" health outcomes and negatively related to a belief in "self control over health" and "provider control over health". In his discussion of this finding, Lau (1982) notes that such a pattern of beliefs is not unrealistic as "there is an

element of uncontrollability or chance in health, and people with many experiences with illness will presumably be more aware of this" (p. 333).

The literature on generalized locus of control beliefs in chronically ill or handicapped children and adults also indicates that such individuals tend to be more external in their health control expectancies than are their healthy counterparts (Eggland, 1973; Goldstein, 1976; Land & Vineberg, 1965; Strickland, 1978). It is interesting to find that, despite reports in the clinical literature suggesting that individuals who live with chronically ill patients also express viewpoints reflecting an external locus of control (see, for example, Chodoff, Friedman & Hamburg, 1964), only one study has specifically examined health locus of control beliefs in families of the chronically ill. Schoememan, Reznikoff and Bacon (1983) studied the relationship between certain personality variables and adaptation to the stress of living with a chronically ill spouse; they found that greater internal locus of control was not associated with better adjustment on the parts of wives of hemodialysis patients, concluding that "a strong perception that one is in control may not be functional in the face of a truly uncontrollable situation".

Despite this growing evidence that individuals who have experienced illness in themselves or in their families maintain an increased belief in external locus of control,

there is a prevailing belief throughout the locus of control literature than an external locus of control is related to poor adjustment (Lowrey, 1981). In reviewing this literature, Strickland (1978) refines this general action, and notes that "findings suggest that the development of an internal orientation could lead to improved health practice for some individuals who have been inclined to believe that life events are beyond their responsibility and more a function of external control" (p. 1205). However, Strickland cautions that internal beliefs are not always facilitative:

> The continued alertness of internals and their attempts at mastery behavior is most appropriate when events are actually controllable. When individuals persist in efforts that bring no relief, then they may find themselves to be actually exacerbating the undesirable characteristics of the situation in which they find themselves. (p. 1205)

Similarly, Wortman and Brehm (1975) have argued that when an outcome is truly uncontrollable, an emphasis on personal causation can be maladaptive.

The relationship between attributional theories of causality and locus of control beliefs is often complex. For example, an individual could hold quite different conceptions about the locus of control of health versus the locus of control of illness. Wallston and Wallston (1978) have noted that a person may have different beliefs regarding positive outcomes (remaining healthy or recovering from illness) than negative outcomes (becoming sick or

sicker). Previous research, as reviewed by Lang-Gunn (1980), has indicated that a healthy person is given more credit for his/her health than an ill person is given blame for his/her illness. Thus, attributions individuals might make for illness may differ from attributions they make for health.

The Family Context for Sibling Response to Childhood Illness

The discussion of sibling response to illness has focussed on developing an understanding of the well sibling's cognitive coping styles--how s/he makes sense of illness. However, the sibling's perceptions of vulnerability and conceptualizations of illness are embedded in the context of family response to illness. Although it is beyond the scope of this review to empirically relate certain family patterns with specific sibling beliefs, it is important to mention here that family members' styles of coping with childhood illness undoubtedly shape and guide the process of adaptation for the sibling. As Kaplan, Smith, Grobstein, and Fishman (1973) argue in their theoretical discussion of family mediation of stress:

> When individuals belong to families they do not resolve their own problems of stress independently, nor are they immune to effects of stress that may be concentrated in another member of the family. . . . the family is uniquely qualified to carry out its stress mediating responsibilities and is in a strategic position to do so. (Kaplan, Smith, Grobstein, & Fishman, 1973, p. 63)

Descriptive data reported in Simons' (1982) indicated that communication styles in the family might be an important mediating factor in the sibling's understanding of illness and manner of coping with illness in the family. Several studies support the notion that open communication about illness strengthens the adaptive capabilities of family members (Christ, 1982; Heffron, 1973; Koocher & O'Malley, 1981; Spinetta, 1978; Townes & Wold, 1977). These researchers have found that a willingness to openly discuss the illness is critical to both the well and ill child's successful adaptation to it.

Townes and Wold (1977) conducted one of the few studies investigating the impact on the healthy sibling of parental communication about the patient diagnosis. They found that poor sibling adjustment was associated with little communication from the mother concerning the illness (in this study, leukemia); the siblings with the best adjustment were those who had obtained information about the leukemia, and who had achieved a realistic understanding of illness.

In sum, the meaning that the well sibling attaches to illness is likely to be influenced by the meaning the illness has for the family, and the manner in which such beliefs are communicated to family members.

Questions Addressed in the Present Study

Simons (1982) found that latency age siblings of ill children were significantly more likely than were matched siblings of well children to attribute responsibility for illness to controllable actions on the part of the ill child. Simons (1982) argued that this attribution of responsibility of illness to the victim was related to the child's need to maintain his or her sense of relative invulnerability. By perceiving the illness as a consequence of irresponsibility or "bad" behavior, the child could not only explain the undeserved suffering of the ill sibling, but could imagine a way of avoiding a similar fate. If the child could not blame someone for these unpredictable and undesirable events, s/he would have been left with the "intolerable conclusion that no one is responsible" and that the events had come about meaninglessly (Chodoff, Friedman & Hamburg, 1964). The idea that the world is a place where undesirable events happen to innocent people on a random basis is particularly frightening to the young child's sense of relative invulnerability.

The present study was designed to investigate whether conceptualizations of illness continue to be different over time for siblings of ill and healthy children. The study compared two matched groups of young adults--one group had lived with a chronically ill sibling during childhood, and the other had lived with a well sibling during childhood--

with respect to their sense of control over their own health, and their perceptions of personal vulnerability to illness. The literature review in this chapter suggests that it is reasonable to expect that the experience of living with an ill sibling during childhood will influence young adults' theories about the world; however, quantitative and descriptive data are necessary to test this notion directly.

To explore this issue, several questions were investigated in the present study by comparing the responses of young adults who had lived with a chronically ill sibling during childhood against the responses of young adults who had lived with a healthy sibling during childhood. These questions were:

(1) Are young adults' beliefs regarding locus of control of health related to whether they lived with a chronically ill sibling?

(2) Are young adults' perceptions of vulnerability to illness related to whether they lived with a chronically ill sibling?

(3) Are young adults' attributions concerning causes and prevention of illness related to whether they lived with a chronically ill sibling?

These three questions were primarily explored on the basis of quantitative analyses conducted on objective data. They were also explored, however, by informal analyses of

qualitative data from clinical interviews. This latter, supplementary research strategy was included because descriptive data in Simons' (1982), gathered from clinical interviews with parents and siblings of chronically ill children, powerfully documented that significant emotional turmoïl is often experienced by well children with an ill sibling. However, these observed reported patterns of emotional and behavioral responses to the illness were often underestimated or obscured in the more quantitative measures. Young adults' retrospective accounts of the effects of sibling illness on their childhoods have not been examined in the clinical or research literature. In addition, no studies have explored the effect of sibling illness on young adults' current feelings about their families and their own futures. In the present study, therefore, young adults' retrospective and current perceptions of the impact of sibling illness on their lives were also assesed.

C H A P T E R I I

METHOD

Introduction

The present study followed a controlled observational design strategy, utilizing retrospective and concurrent self and direct observational data. This study attempted to explore empirically several specific hypotheses about the lasting effects of chronic sibling illnesses experienced during childhood, on young adults. Utilizing quantitative measures, comparisons were made between young adults who as children were healthy siblings of ill children, and young adults who as children were were healthy siblings of well children. These data were gathered to test two specific hypotheses: (1) whether the attributions of responsibility for illness and for prevention of illness were different for these two groups and (2) whether these two groups differed in their senses of control over their own health, and senses of vulnerability to illness. Qualitative data were also collected through semi-structured individual interviews with the young adults having ill siblings during childhood. These data were collected to assess these young adults' perceptions of (1) the impact of sibling illness on these subjects' lives as children and as young adults and (2) the coping strategies these subjects recollected having utilized

as children in adapting to the stress of living with a chronically ill sibling.

The subjects in this study were young adults, approximately ten years older than the subjects in the study inspiring this one (Simons, 1982). In order to allow for the emergence of similar differences in the meanings and effects of sibling illness on the lives of the present subjects, several measures were adapted from the previous study (Concept of Illness Task, Vulnerability to Illness Task, Clinical Interview). Two new measures were included as well. The Multidimensional Health Locus of Control Scale (Wallston, Wallston & DeVellis, 1978) specifically assesses belief in relation to locus of control of health. The Likelihood of Illness Measure (modelled after a similar measure by Lang-Gunn, 1980) assesses perceived likelihood of developing personal illness in relation to the average person.

Subject Recruitment Procedures

The experimenter recruited subjects by handing out descriptions of the study to undergraduates enrolled in large lecture courses at a state university, as well as by placing notices on the bulletin boards of the psychology department building. Subjects were asked to complete an Initial Screening and Information Form (please see Appendix

A) if interested in participating in the study. Subjects received course credit in exchange for their participation.

Subjects

Experimental group subject selection criteria were designed to include healthy young adults who had lived with a chronically ill sibling for a significant period of time during childhood. Chronic illness in this study was defined to include those long term illnesses which have been shown previously in the literature to have a significant impact on family life (Allan, 1974; Apley, Barbour, & Westmacott, 1967; Binger, 1973, Burton, 1975; Crain, Sussman, & Weil, 1966; Davis, 1963; Dubo, 1950; Farkas & Schnell, 1973; Freidrich, 1977; Grave, 1974; Gyulay, 1975; Hewett, Newsom, and Newsom, 1970; Hung, 1973; Kew, 1975; Kruger, 1980; Kupst and Schulman, 1980; Maxell & Gar, 1962; McKeever, 1983; McCollum & Gibson, 1970; Meyerowitz & Kaplan, 1967; Neil, 1970; Salk, Hilgarten, & Granich, 1972; Sargent, 1982; Siegel and Kornfield, 1980; Sourkes, 1977; Turk, 1964; Voyesy, 1975): diabetes, cystic fibrosis, muscular dystrophy, severe asthma, cancer, heart disease, thyroid disease, epilepsy, inflammatory bowel disease, spina bifida. Potential experimental subjects who had experienced parental chronic illness or death, sibling death, sibling mental retardation, or who were themselves chronically ill were excluded from consideration, due to the potentially

powerful and complicating effects of these factors on responses to sibling illness. The following criteria were employed then to select experimental subjects:

1. The subject had lived with the ill sibling for at least 10 years.
2. No members of the subject's immediate family were deceased.
3. No members of the subject's immediate family, aside from the ill sibling, were chronically ill.
4. The subject's ill sibling was not mentally handicapped.

Four hundred eleven potential subjects (280 females and 141 males) completed the Initial Screening and Information Form. Of these, 32 (8%) fit the experimental group selection criteria, which is a level comparable to the percentage of families in the general population with chronically ill children (Gortmaker & Sappenfield, 1984). Five of these 32 potential experimental subjects could not be tested: one person declined to be tested, one subject moved from the area, and three people could not be contacted or scheduled for testing. Accordingly, 27 healthy young adult siblings of chronically ill children were included in the experimental group. Their distribution across the physical conditions afflicting their siblings was as follows: diabetes (26%), severe asthma (22%), inflammatory bowel disease (11%), leukemia or Hodgkin's disease (7%),

heart disease (7%), thyroid disease (7%), epilepsy (7%), muscular dystrophy (7%), and spina bifida (4%).

The control group consisted of 27 physically healthy individuals who had lived with a healthy sibling for at least ten years during childhood. These subjects were also selected from the pool of 411 potential subjects who completed the Initial Screening and Information Form. Due to the large pool of potential control subjects (N = 411 minus 32, or 379), it was possible to match control subjects to experimental subjects on the following variables which were described earlier as factors which may potentially influence sibling response to childhood illness:

(1) age of subject, within one year

(2) sex of subject

(3) sex of sibling

(4) whether sibling was older or younger than subject

(5) number of siblings

Eight potential control subjects who were initially selected were replaced because they could not be contacted or scheduled; one control subject was dropped and replaced because he failed to properly complete the procedures. The mean age of subjects was 19 (range = 18 - 34). Fifty-six percent of the subjects were female and 44% were male; 41% of the siblings were female and 59% were male. Forty-one percent of the siblings were older than the subject and 59% were younger. The mean number of siblings was

3.55 (range = 1 - 8). A listing of the characteristics of each experimental and control matched pair is presented in Table 1.

The experimental and control groups were balanced for two additional variables: family income (median income was above $25,000) and maternal education (modal education was completion of high school). A summary of variables balanced for experimental and control groups is presented in Table 2.

Measures

Concept of Illness Task

Studies investigating individuals' understandings of illness have utilized either stimulus pictures illustrating some scene of illness, or questionnaire protocols (Bibace & Walsh, 1978; Blos, 1978; Carandang, Folkins, Hines & Steward, 1979; Gellert, 1961; Gochman, 1971; Kister & Patterson, 1980; Peters, 1978; Simeonson, 1979). Unfortunately, these published reports seldom provide copies of the stimulus pictures or protocols; moreover, the interviews are generally not structured procedures. The Concept of Illness Task, designed specifically for Simons' (1982) previous study of latency age children's responses to sibling illness, combines a stimulus picture with a structured interview protocol to assess subject's understandings of illness. In this procedure, a drawing of a gender-ambiguous person in a hospital bed, surrounded by

TABLE 1

CHARACTERISTICS OF EXPERIMENTAL AND CONTROL MATCHED PAIRS

Pair #	Sex of Subject	Age of Subject	Number of Siblings	Sibling Older or Younger	Sex of Sibling
1	male	eighteen	three	younger	male
2	male	nineteen	three	older	male
3	female	eighteen	seven	younger	male
4	male	eighteen	three	younger	male
5	male	twenty	two	older	female
6	female	nineteen	two	older	female
7	male	twenty	one	younger	female
8	female	eighteen	two	younger	male
9	female	twenty-two	three	younger	female
10	male	nineteen	five	older	male
11	male	twenty	two	younger	male
12	female	twenty	four	older	male
13	male	twenty-one	one	younger	female
14	female	twenty	three	younger	male
15	female	twenty	seven	younger	male
16	male	nineteen	one	younger	male
17	male	nineteen	four	younger	male
18	female	eighteen	three	younger	female

TABLE 1 (continued)

CHARACTERISTICS OF EXPERIMENTATAL AND CONTROL MATCHED PAIRS

Pair #	Sex of Subject	Age of Subject	Number of Siblings	Sibling Older or Younger	Sex of Sibling
19	female	twenty	six	older	male
20	female	eighteeen	two	older	female
21	female	twenty-two	eight	older	female
22	male	twenty-one	one	older	female
23	female	twenty-one	two	younger	male
24	male	thirty-four	two	older	female
25	female	nineteen	three	younger	male
26	female	twenty	seven	younger	male
27	female	nineteen	four	older	female

NOTE. Example: Pair 1 refers to two subjects, one experimental and one control.

They are both eighteen year old males, both have three siblings, and both have a younger brother.

TABLE 2

VARIABLES BALANCED FOR EXPERIMENTAL CONTROL GROUPS

	Experimental	Control
1. Maternal Education		
Junior High	0	1
High School	11	12
Some College	8	7
College	3	3
Graduate Work	5	4
2. Family Income		
0-$5,000	0	0
$5,001-$10,000	1	0
$10,001-$15,000	1	1
$15,001-$20,000	3	3
$20,001-$25,000	3	5
Over $25,000	19	18

parents and a sibling, is presented to the subject. The subject is asked to respond in written form to questions designed to identify attributions of responsibility for illness. (A photocopy of the stimulus picture and interview protocol is presented in Appendix B). The task also includes questions regarding the subjects' beliefs about responsibility for health. Significant differences between health siblings of ill children and healthy siblings of well children were observed utilizing this measure in the study of latency age children (Simons, 1982).

Multidimensional Health Locus of Control Scale

The Multidimensional Health Locus of Control Scale (MHLC) is a health specific locus of control measure developed by Wallston, Wallston and DeVellis (1978). This scale assesses whether the individual believes his or her health status is a function of "chance", the actions of "powerful others", or one's own "internal" beliefs and behaviors. The Internal scale of the test measures the degree to which the individual perceives his or her health status as under his or her own control. The External scale has two subscales: the Powerful Others subscale evaluates the degree to which the individual attributes his or her health status as influenced by family, friends, peers, and health care professionals, while the Chance subscale measures the degree to which the individual views chance or fate as responsible for health status.

The MHLC instructs individuals to indicate the extent to which they agree or disagree with a series of belief statements such as "when I stay healthy I'm just lucky", using a six point Likert Scale response format. The psychometric properties of the MHLC Scale have been examined in several previous studies. Wallston, Wallston and DeVellis (1978), and Wallston and Wallston (1982) in studies of college undergraduates and health fair participants, reported alpha coefficients for the three MHLC scales ranging from .67 to .77. Intercorrelations among the scales revealed that the Internal and Powerful Others dimensions were statistically independent, Internal and Chance were correlated negatively, and Powerful Others and Chance were correlated positively.

Studies utilizing patient populations suggest that the use of MHLC is both a reliable and valid measure of health beliefs. Harke and Kunce (1982) studied the factorial structure of the MHLC in a sample of 86 medical patients; results confirmed the factorial structure of the locus of control items as falling into the three separate subscales. Of note is their finding that the Powerful Others and Chance subscales correlated significantly and negatively with education. Similarly, Winefield (1982) found that the Powerful Others subscale was correlated significantly with age and social status, such that older subjects of lower social status expressed significantly greater faith in the

ability of powerful others to control their health. Russell and Ludenia (1983), examining the psychometric properties of the MHLC with inpatients being treated for alcohol dependency, reported that the three subscales appeared to measure largely independent dimensions of locus of control beliefs specifically related to health. And finally, MHLC has been utilized successfully to study the relationship between locus of control and health information seeking (DeVellis, Devellis, Wallston & Wallston, 1980; Germer & Price, 1981; Wallston & Wallston, 1981), preventative health behaviors (Fischberg, 1979; Gossler, 1980; Guske, 1980; Pill, 1981), responses to disability (DeVellis, DeVellis, Wallston & Wallston, 1980; Wallston & Wallston, 1981), symptoms (Nice, 1980), adherence to medical regimens (Goldstein, 1980; Hatz, 1978; Levin & Schulz, 1980), and responses to health systems (Levin & Schulz, 1980; Nicholson, 1980). A copy of the MHLC may be seen in Appendix C.

Vulnerability to Illness Questionnaire

The Vulnerability to Illness Questionnaire was designed by Simons (1982) to assess individuals' concerns about their own health, including somatic complaints and anticipation of developing minor illnesses. With this measure, subjects are asked how often they were ill with specific health problems during the previous six months and how often they expect to

become ill with these same specific health problems during the next six months. The Vulnerability to Illness Questionnaire for this study was modified from Simons (1982), in order to take into account the different health concerns of older subjects. A copy of the Vulnerability to Illness Questionnaire may be seen in Appendix D.

Likelihood of Illness Scale

The Likelihood of Illness Scale for this study was modelled after Lang-Gunn's (1980) measure of perceived vulnerability to illness. In this measure, subjects judge the likelihood that (a) they themselves, and (b) the average person in this country, will develop specific illnesses or conditions at some point in their lives. Some psychometric data are available on this scale: in a study of observers' perceptions of the physically ill, Lang-Gunn (1980) found that respondents (238 college students) rated the likelihood of their developing a specific illness as significantly less than the likelihood of the average person developing that illness. In the present study three of the illnesses specified are acute (kidney infection, pneumonia, and food poisoning), while three are chronic (diabetes, coronary heart disease, and cancer). A copy of the Likelihood of Illness Scale is presented in Appendix E.

Family Background Form

The Family Background Form was developed for this study to investigate retrospectively reported sources of support and stress for the individual and his/her family of origin. For both experimental and control group subjects, questions were included to tap variables such as family structure, social environment, and social supports. Current demographic variables, such as their choice of major in college, were assessed as well. Experimental group subjects answered an additional set of questions regarding the ill sibling's medical problem, the subject's involvement in patient care, and the subject's understanding of the illness over time. A copy of the Family Background Form may be seen in Appendix F.

Clinical Interview

An exploratory, semi-structured interview with experimental group subjects was administered by the investigator to directly assess the reported and apparent impacts of sibling illness on their lives. During this interview, subjects were asked to comment specifically about relationships with family members and peers, knowledge about the ill sibling's condition, and feelings about the effect of the illness upon themselves and their families. A list of sample questions covered in this interview is presented in Appendix G.

Procedure

A trained female research assistant administered the non-interview tasks individually to each subject, after subjects completed the Informed Consent Form (Appendix H). Instruments were presented in a fixed order; the test sequence designed to start with the most projective, unstructured tasks and end with the least projective and more structured tasks was as follows: Concept of Illness Task, Multidimensional Health Locus of Control Scale, Likelihood of Illness Scale--Form I, Vulnerability to Illness Questionnaire, Likeliness of Illness Scale--Form II, and Family Background Form. (The separation of the two Likelihood of Illness Scale forms was intended to minimize the degree of influence that answers to the first form would exert over answers to the second.) Twenty-three experimental subjects who indicated on the Family Background Form a willingness to participate in the Clinical Interview portion of the study were contacted by the investigator for a second meeting, which was autiotaped and later transcribed.

Data Preparation and Reduction

Concept of Illness Task

Subjects' responses to the Concept of Illness Task were scored on three dimensions: Reason for the Story Child's Hospitalization, Cause of the Story Child's Hospitalization, and Prevention of Future Illness or Hospitalization. A

content analysis of the response pool indicated that for each dimension, subject responses could be sorted into meaningful relevant categories. Consequently, a coding system was developed for each of these three dimensions, operationalizing each category. The Concept of Illness Coding System, with examples of content coded into each category follows:

A. Reason for Story Child's Hospitalization

1. Severe illness or injury: cancer, diabetes, heart attack, paralysis.
2. Operation: tonsils or appendix removed, hernia, gall bladder, ulcers.
3. Mild injury or illness or unspecified reason: fatigue, headaches, drug overdose, medical tests, virus.

B. Cause of Story Child's Hospitalization

1. Self behavior: intentional or unintentional; result of fall, lifting, overexertion; taking risks, not taking care of oneself.
2. Chance/heredity/environment: "natural causes", other person's behavior, or nothing specified.

C. Prevention of Future Illness or Hospitalization

1. Self behavior: "being more careful", exercise, not smoking, reducing stress.

2. Medical/nothing specified/chance: following specific medical advice, nothing specified, or chance.

Categories were not mutually exclusive; as a result, on occasion individual responses could be assigned to multiple categories. When this was the case, category assignment was based on the single theme judged to be predominant; if two themes were equally competing, the response was assigned to both categories. Individual responses were assigned to multiple categories on two occasions in the Cause of Story Child's Hospitalization dimension (this consisted of responses of one experimental subject and one control subject), and on six occasions on the Prevention of Future Illness or Hospitalization dimension (this consisted of responses of three experimental subjects and three control subjects).

The experimenter and a clinical psychologist each scored the responses independently, blind to respondent condition. Reliability was indexed by percent agreement, calculated by dividing the number of agreements by the number of coded responses for all subjects. Table 3 reports the percent agreement for each category. The average percent agreement across categories was .96.

Multidimensional Health Locus of Control Scale

A score for each of the three subscales on the MHLC (Chance, Powerful, Others, and Internal) was obtained by

TABLE 3

RELIABILITY OF CATEGORIES IN CONCEPT OF ILLNESS TASK

Category	Percent Agreement
A. Reason for Story Child's Hospitalization	
1. Severe Illness or Injury	.96
2. Operation	1.00
3. Mild injury/illness or nothing specified	.96
B. Cause of Story Child's Hospitalization	
1. Self Behavior	.95
2. Chance/Heredity/Environment	.95
C. Prevention of Future Hospitalization	
1. Self Behavior	.97
2. Medical/Nothing Specified/Chance	.97

summing the values circled by the subject for each statement included in that subscale. For example, the items for the Internal subscale consisted of six statements. Thus, a subject's potential score for the Internal scale ranged from 6 (strongly disagreed with all statements) to 36 (strongly agreed with all statements).

Vulnerability to Illness Questionnaire

The values circled by the subject regarding the number of times s/he was ill with a specific health problem during the previous six months resulted in a score for each illness condition in the general category of Number of Times Ill in the Last Six months. The values circled by the subject regarding number of times s/he expected to experience a specific health problem during the next six months resulted in a score of each illness condition in the general category of Number of Times Expect to Become Ill in Next Six Months. The values ranged from 1 - 20 for each illness condition.

Likelihood of Illness Scale

The score for each of the six illness conditions on the Likelihood of Illness Scale--Form 1--was obtained by summing the values circled by the subject regarding the likelihood of the self developing that particular condition. The score for each illness condition on Form II of the Likelihood of Illness scale was obtained in a similar manner by summing the values circled by the subject regarding the likelihood

of the average person developing that particular condition. Thus, on each Form a subject's potential score for a specific illness condition, such as diabetes, ranged from 1 (extremely unlikely) to 6 (extremely likely).

Family Background Form

Subjects' choice of major, as indicated on the Family Background Form, were initially organized into eight content categories: Psychology; Nursing/Allied Health; Law/Political Science/Education; Business/Marketing/Hotel Administration; Computer/Engineering/Math; Public Relations/Advertising/ Journalism; Art/Leisure Studies/Languages; and Undecided. These categories were then combined into two general categories: (1) those directed toward the "helping" professions (Psychology, Nursing/Allied Health, Law/Political Science/Education) and, (2) those directed toward "other" professions (Business/ Marketing/ Hotel Administration, Computer/Engineering/Math, Public Relations/Advertising/Journalism, Art/Leisure Studies/Languages, Undecided).

CHAPTER III

RESULTS

The results of statistical analyses of the data are presented in four sections. The first three sections correspond to the hypotheses stated at the end of Chapter One; the last section describes information gathered from the Family Background Form on subjects' major course of study.

Health Locus of Control

The first question asked whether young adults' beliefs regarding locus of control of health are related to whether they lived with a chronically ill sibling. In order to test for differences between the experimental and control groups on the three factors of the Multidimensional Health Locus of Control Scale, data on each factor score (Internal, Chance, Powerful Others) were subjected to *t*-test analyses. On the Internal beliefs factor a significant difference was observed between the experimental and control groups ($t_{(52)} = -2.77$, $p < .0076$ with the experimental group's mean being significantly lower than was the mean of the control group. On the Chance belief factor, a significant difference was observed between the experimental groups as well ($t_{(52)} = 2.63$, $p < .0111$) with the experimental group's mean being significantly higher than was the mean of the

control group. No significant differences were observed between the means of the experimental and control groups ($t_{(52)} = -1.50$, $p < .1391$) on the Powerful Others factor. The means, standard deviations, and ranges for both the experimental and control groups on the three factors of the MHLC may be seen in Table 4.

Vulnerability to Illness

The second question asked whether young adults' perceptions of vulnerability to illness are related to whether or not they lived with a chronically ill sibling. Two measures were used to assess subjects' perceptions of vulnerability to illness: the Vulnerability to Illness Questionnaire and the Likelihood of Illness Scale. Each measure will be discussed separately.

Vulnerability to Illness Questionnaire

Table 5 reports the means, standard deviations, and ranges for experimental and control subjects when asked how many times they had experienced five specific health problems, missed classes due to illness, or sought medical treatment, in the last six months. Table 6 reports the means, standard deviations, and ranges for these same subjects when asked how many times they expected to experience these same specific health conditions in the next six months. Total scores did not yield significant differences between experimental and control groups for

TABLE 4

Summary Data for the Multidimensional Health Locus of Control Scale: The Internal, Chance and Powerful Others Subscales

Subscale	Experimental[a]			Control[b]		
	M	SD	Range	M	SD	Range
Internal	25.78	3.09	19 - 32	28.15	3.18	21 - 35
Chance	20.04	3.57	13 - 27	16.67	5.63	7 - 28
Powerful Others	16.33	2.75	10 - 21	18.00	5.07	6 - 31

[a] $\underline{n} = 27$

[b] $\underline{n} = 27$

TABLE 5

Summary Data for Vulnerability to Illness Questionnaire: Number of Times Reported Ill in Last Six Months

Illness Category	Experimental[a] M	SD	Range	Control[b] M	SD	Range
Cold	2.70	2.14	0 - 10	2.67	1.71	1 - 8
Accident	0.96	1.45	0 - 4	0.78	0.97	0 - 4
Headache	4.52	4.38	0 - 15	5.59	5.91	0 - 20
Stomach Flu	2.07	4.43	0 - 19	1.41	2.50	0 - 12
Fever	1.44	2.33	0 - 10	1.88	1.24	0 - 4
Miss Classes	1.89	2.34	0 - 10	1.96	2.29	0 - 10
Seek Medical Treatment	1.33	2.09	0 - 8	1.04	1.93	0 - 10
Total	14.93	14.19	3 - 63	14.63	9.92	1 - 42

[a] n = 27

[b] n = 27

TABLE 6

Summary Data for Vulnerability to Illness Questionnaire: Number of Times Expect to Become Ill in Next Six Months

Illness Category	Experimental[a]			Control[b]		
	M	SD	Range	M	SD	Range
Cold	1.41	1.34	0 - 6	1.85	1.37	0 - 6
Accident	0.78	1.74	0 - 8	0.75	0.81	0 - 2
Headache	3.78	5.24	0 - 20	3.63	3.93	0 - 15
Stomach Flu	1.70	4.30	0 - 20	0.48	0.64	0 - 2
Fever	1.00	2.04	0 - 10	0.81	0.88	0 - 3
Miss Classes	1.15	1.73	0 - 7	0.96	1.16	0 - 3
Seek Medical Treatment	1.22	2.10	0 - 10	0.93	1.94	0 - 10
Total	11.04	12.37	0 - 59	9.41	5.06	0 - 20

[a] $\underline{n} = 27$

[b] $\underline{n} = 27$

number of times ill in last six months ($t_{(52)} = .089$, n.s.) or number of times expect to become ill in next six months ($t_{(52)} = .63$, n.s.) The difference between Number of Times Ill in Last Six Months minus Number of Times Expect to Become Ill in Next Six Months which could be construed as an adjusted index of vulnerability to illness, was also calculated; Table 7 reports the means, standard deviations, and ranges for experimental subjects on this constructed variable. Total scores did not yield significant differences between the experimental and control groups ($t_{(52)} = 0.62$, n.s.), however, on this variable.

Likelihood of Illness Scale

The Likelihood of Illness Scale measures subjects' ratings of the likelihood of their developing a particular illness at some point in their lives and ratings of the likelihood of the average person developing a particular illness at some point in his/her life. Thus, scores could be divided into Self and Average Person categories. Table 8 reports the means and standard deviations for experimental and control subjects in the category of Likelihood of Self Becoming Ill; Table 9 reports the means and standard deviations of experimental and control subjects in the category of Likelihood of Average Person Becoming Ill.

In addition, type of illness could be divided into two categories: Chronic Illness (cancer, coronary heart disease, diabetes) and Acute Illness (food poisoning, kidney

TABLE 7

Summary Data for Vulnerability to Illness Questionnaire: Number of Times Reported Ill in Last Six Months Minus Number of Times Expect to Become Ill in Next Six Months

Illness Category	Experimental[a]			Control[b]		
	M	SD	Range	M	SD	Range
Cold	1.30	1.77	-1 - 8	0.81	1.36	-2 - 4
Accident	0.18	1.14	-4 - 2	0.04	0.85	-2 - 2
Headache	0.74	3.33	-10 - 7	1.96	3.44	-2 - 15
Stomach Flu	0.37	1.82	-5 - 7	0.93	0.93	-1 - 11
Fever	0.44	1.12	-1 - 4	0.37	1.01	-1 - 2
Miss Classes	0.74	1.35	-1 - 5	1.00	1.82	-2 - 7
Seek Medical treatment	0.11	1.50	-2 - 6	0.11	0.70	-2 - 1
Total	3.89	8.42	-12 - 36	5.22	7.29	-6 - 30

[a] $\underline{n}$ = 27

[b] $\underline{n}$ = 27

TABLE 8

Summary Data for Likelihood of Illness Scale: Likelihood of Self Becoming Ill

Category	Experimental[a] M	SD	Control[b] M	SD
Food Poisoning	3.66	1.52	3.14	1.26
Diabetes	2.96	1.63	2.37	1.18
Coronary Heart Disease	2.67	1.18	2.74	1.06
Kidney Infection	2.67	1.27	2.67	1.18
Cancer	3.30	1.17	3.26	1.13
Pneumonia	3.30	1.49	3.78	1.31
Total	18.56	4.38	17.96	3.82

[a] $n = 27$

[b] $n = 27$

TABLE 9

Summary Data for Likelihood of Illness Scale: Likelihood of Average Person Becoming Ill

Category	Experimental[a]		Control[b]	
	M	SD	M	SD
Food Poisoning	3.89	1.25	3.56	1.88
Diabetes	3.18	1.24	3.63	0.89
Coronary Heart Disease	4.52	1.09	3.63	1.11
Kidney Infection	3.37	1.27	3.22	1.01
Cancer	4.59	1.25	3.85	1.20
Pneumonia	3.63	1.25	3.85	1.13
Total	23.18	5.75	21.33	4.79

[a] $\underline{n} = 27$

[b] $\underline{n} = 27$

infection, pneumonia). Table 10 reports the means and standard deviations for the experimental and control subjects when responses in the category of Chronic Illness were combined, and means and standard deviations for the experimental and control subjects when responses in the category of Acute Illness were combined.

Finally, within each of the illness categories (Chronic and Acute), scores for Likelihood of Self Becoming Ill and Likelihood of Average Person Becoming Ill scores could be combined. Thus, Table 11 reports the means and standard deviations for the experimental and control groups when Likelihood of Self Becoming Ill and Likelihood of Average Person Becoming Ill was calculated within the Chronic Illness category; Table 12 reports the means and standard deviations for the experimental and control groups when the Likelihood of Self Becoming Ill and Likelihood of Average Person Becoming Ill was calculated within the Acute Illness category.

Significant differences were observed between the experimental and control groups in the category of Likelihood of Average Person Developing Chronic Illness, ($\underline{t}_{(52)} = 2.21$, $p < .03$). The experimental group gave significantly higher scores than did the control group in estimating the likelihood of the average person developing chronic illness. When the category of Likelihood of Average Person Developing Chronic Illness was broken down into each

TABLE 10

Summary Data for Likelihood of Illness Scale: Chronic Versus Acute Illness

Category	Experimental[a]		Control[b]	
	M	SD	M	SD
Chronic Illness	21.22	4.69	19.07	3.80
Acute Illness	20.52	5.19	20.22	5.03

[a] n = 27

[b] n = 27

TABLE 11

Summary Data for Likelihood of Illness Scale: Chronic Illness Category

Category	Experimental[a]		Control[b]	
	M	SD	M	SD
Likelihood of Self Becoming Ill	8.93	2.72	8.37	2.15
Likelihood of Average Person Becoming Ill	12.29	2.83	10.70	2.46

[a] $n = 27$

[b] $n = 27$

TABLE 12

Summary Data for Likelihood of Illness Scale: Acute Illness Category

Category	Experimental[a] M	SD	Control[b] M	SD
Likelihood of Self Becoming Ill	9.63	3.09	9.59	1.31
Likelihood of Average Person Becoming Ill	10.89	3.27	10.63	3.03

[a] n = 27

[b] n = 27

illness condition, significant differences were observed between the experimental and control groups for the Cancer condition, ($t_{(52)} = 2.23$, $p < .03$) and for the Coronary Heart Disease condition ($t_{(52)} = 2.97$, $p < .0045$). The experimental group's belief that the average person would develop these conditions was significantly higher than was the control group's.

No significant differences were observed between experimental and control groups in the general categories of Likelihood of Self Becoming Ill, ($t_{(52)} = .53$, n.s.), Likelihood of Average Person Becoming Ill, ($t_{(52)} = 1.29$, n.s.) or Acute Illness ($t_{(52)} = .21$, n.s.). In the general category of Chronic Illness, t-test analyses revealed a nonsignificant tendency for the experimental group to give higher scores than did the control group, ($t_{(52)} = 1.85$, $p < .07$).

Attributions for Illness

The third question asked whether young adults' attributions concerning causes and prevention of illness are related to whether they lived with a chronically ill sibling. To test for differences between the experimental and control group on the three dimensions from the Concept of Illness Task, (Reason for Story Child's Hospitalization, Cause of Story child's Hospitalization, and Prevention of Future Illness or Hospitalization), data were submitted to

chi-square analyses. In addition, subject attributions for the Cause of Story Child's Hospitalization were compared to subject attributions for the Prevention of Future Illness or Hospitalization.

Table 13 reports the response categories of experimental and control subjects when asked to explain what was wrong with the story child; Table 14 reports the response categories of subjects when asked to describe the cause of the story child's hospitalization; and Table 15 reports the response categories of subjects when asked how the story child might avoid future illness or hospitalization. There were no significant differences between the experimental and control groups on any of these dimensions (Reason for Story Child's Hospitalization: $\underline{X}^2_{(2)} = 5.59$, $\underline{p} < .10$; Cause of Story Child's Hospitalization $\underline{X}^2_{(1)} = 3.60$, $\underline{p} < .10$, or Prevention of Future Illness or Hospitalization $\underline{X}^2_{(1)} = .272$, n.s.). However, when experimental group responses for cause of hospitalization were compared to their responses for prevention of hospitalization, there was a significant difference in attributions, ($\underline{X}^2_{(1)} = 5.78$, $\underline{p} < .025$); the experimental group attributed the cause of hospitalization to chance, but attributed the prevention of hospitalization to self behavior. A similar difference in attributions made for cause and prevention of hospitalization was not found in the control group ($\underline{X}^2_{(1)} = .274$, n.s.). Table 16 reports the

TABLE 13

Reasons for Story Child's Hospitalization: Experimental and Control Group Responses[a]

Reason for Hospitalization	Number of Experimental	Number of Control
Severe Illness or Injury	10	9
Operation	13	7
Mild Injury/Illness or Nothing Specified	4	11

[a] $\underline{X}^2_{(2)} = 5.59$, $\underline{p} < .10$

TABLE 14

Causes of Story Child's Hospitalization: Experimental and Control Group Responses[a]

Cause of Hospitalization	Number of Experimental	Number of Control
Self Behavior	8	15
Chance/Heredity/Environment	20	13

[a] $\underline{X}^2_{(1)} = 3.60$, $\underline{p} < .10$

TABLE 15

Prevention of Future Illness or Hospitalization
Experimental and Control Group Responses[a]

Method of Prevention	Number of Experimental	Number of Control
Self Behavior	18	16
Medical/Nothing Specified/Chance	12	14

[a] $\underline{X}^2_{(1)} = .272$, n. s.

attributions for cause versus prevention of hospitalization for the experimental group; Table 17 reports the attributions for cause versus prevention of hospitalization for the control group.

Major Course of Study

In an effort to assess whether living with a chronically ill sibling was related to young adults' professional aspirations, subjects were asked on the Family Background Form to describe their major in college. Table 18 presents the major course of study for experimental and control group subjects. When the categories were combined into two general categories: "helping professions" and "other", significant differences were observed between the experimental and control groups. The experimental subjects were significantly more likely to choose majors in the "helping professions" than were control subjects ($\underline{X}^2(1) = 4.79$, $\underline{p} < .05$).

TABLE 16

Cause Versus Prevention of Hospitalization: Experimental Group Responses[a]

Attribution	Cause of Hospitalization	Prevention of Hospitalization
Self Behavior	8	18
Chance/Heredity/Environment Nothing Specified	20	12

[a] $\underline{X}^2_{(1)} = 5.78$, $\underline{p} < .025$

TABLE 17

Cause Versus Prevention of Hospitalization: Control Group Responses[a]

Attribution	Cause of Hospitalization	Prevention of Hospitalization
Self Behavior	15	16
Chance/Heredity/Environment/ Nothing Specified	13	14

[a] $\underline{\chi}^2_{(1)} = .274$, n. s.

TABLE 18

Major Course of Study
Experimental and Control Group Responses[a]

Category	Number of Experimental	Number of Control
"Helping Profession"		
Psychology	10	2
Nursing/Allied Health	4	3
Law/Political Science/Education	2	3
"Other"		
Business/Marketing/Hotel Administration	5	8
Computer/Engineering/Math	1	3
Public Relations/Advertising/ Journalism	0	4
Art/Leisure Studies/Languages	2	1
Undecided	3	3
Total "Helping Professions"	16	8
Total "Other"	11	19

[a] $\underline{X}^2_{(1)} = 4.79$, $\underline{p} < .05$

CHAPTER IV

DISCUSSION

Introduction

This chapter is composed of four related sections. The first section briefly reviews the major quantitative findings of the present study in the context of the questions posed at the end of Chapter One. The second section presents a theoretical discussion of these findings on siblings' conceptualizations of illness in terms of social psychological formulations on reactions to misfortune and the development of health locus of control beliefs. The third section examines the study's descriptive data in regard to the underlying emotional responses of the well sibling, and the adaptive strategies that the well sibling and the family as a whole utilize to cope with the stresses of living with an ill child. This discussion will make use of a comparison between the present study's findings with young adult siblings of ill children and Simons' (1982) study with latency age siblings of ill children. Finally, in the fourth section, methodological issues will be considered as well as potential directions for future research.

Review of Quantitative Findings

The first question in the present study asked if whether young adults' beliefs regarding locus of control of

health were related to whether or not they had lived with an ill sibling during childhood. Results of the Multidimensional Health Locus of Control Scale revealed that young adults who had lived with an ill sibling during childhood maintained a stronger belief in chance determining health status than did their peers who had not lived with an ill sibling. Similarly, in comparison to controls, these young adult siblings of ill children were less likely to believe that one's behavior plays a major role in determining subsequent health. Although both experimental and control group subjects overall maintained greater belief in Internal rather than Chance health locus of control, the experimental group had significantly higher Chance scores and significantly lower Internal scores on the Multidimensional Health Locus of Control Scale than did the control group.

The second question asked whether young adults' perceptions of vulnerability to illness were related to whether or not they lived with a chronically ill sibling during childhood. In contrast to Simons' (1982) results, in which it was found that latency age siblings of ill children believed they would be healthier in the future, the experimental subjects in the present study expressed similar perceptions of vulnerability to illness as did the control group. On both the Vulnerability to Illness Task and the Likelihood of Illness Scale, these young adults who had lived with ill siblings reported similar perceptions of past

illness experiences and potential future illness experiences as did those young adults who had lived with a well sibling. However, the experimental group perceived the likelihood of the average person experiencing chronic illness, particularly coronary heart disease and cancer, as being significantly higher than did the control group.

The third question asked if young adults' attributions for causes and prevention of illness were related to living with a chronically ill sibling. Unlike Simons' (1982) findings with latency age children, the experimental and control groups did not differ significantly in their attributions on the Concept of Illness Task. However, there was a trend for the experimental group, in contrast to the control group, to attribute the cause of illness to factors other than self behavior, such as chance or fate. In addition, whereas there were significant differences between the attributions the experimental group made for cause and for prevention of illness (they viewed the cause as due to chance rather than self behavior, but prevention as due to self behavior rather than chance), this same differential pattern did not hold for the control group.

In summary, the quantitative results from this study indicate that living with a chronically ill sibling during childhood is related to young adults' conceptions of illness, such that these young adults demonstrate a stronger belief in the role of chance determining health and illness

than do individuals who have not lived with an ill sibling. The experience of living with a chronically ill sibling is also associated with young adults' beliefs in the prevalence of illness in the general population; their estimate of the likelihood of the average person developing a chronic disease is much higher than the estimate of peers who have not lived with a chronically ill sibling. In addition, in contrast to young adults who did not grow up with ill siblings, the attributions that these young adults make for causes of illness differed significantly from the attributions they make for prevention of illness. Finally, assessments of whether living with a chronically ill sibling was related to young adults' professional aspirations found that siblings of ill children were significantly more likely to choose majors in the "helping professions" than were siblings of well children.

The Impact of Chronic Childhood Illness on Healthy Siblings' Conceptualizations of Illness

In the introduction to this discussion, social psychological theories regarding reactions to misfortune were presented in terms of the potential effect of sibling illness on locus of control beliefs, perceptions of vulnerability and assumptions of the world as just and controllable. This section will discuss the quantitative findings in regard to these interrelated social psychological formulations.

Health Locus of Control Beliefs

The findings of the present study indicate that a history of living with a chronically ill sibling is associated with certain health control beliefs. Young adults who lived with an ill sibling demonstrated an increased belief in Chance locus of control of health and decreased belief in Internal locus of control of health as compared to their peers. This finding is valuable for the information it provides about the development of health locus of control beliefs as well as the specific direction of those beliefs.

As described in the literature review, the two studies which investigated the relationship between early illness experiences and health beliefs found that health locus of control beliefs may originate in relation to these early illness experiences (Lau, 1982; Tolar, 1978). The results of the present study provide further evidence of how the experience of sibling illness in the family may influence the development of these beliefs. It can be argued that the long history of attempting to maintain control over health situations leads these young adults to believe that such efforts do not necessarily result in increased health. Material from the interview portion of this study suggests that this belief may have been the case for many subjects:

> You never think it's going to happen to your family and when it does, you look at things with a different perspective. We were a healthy family and then suddenly, "bam". It changed us. Now,

> even when he's in remission, I think anything can happen, he can change for worse or he can change for better. Whatever comes up, it's beyond your control, no matter how good he is about his treatments. (sister of boy with leukemia)

> Because of what happened with Tommy, I think I have more of a belief that things just happen and that's just how it's meant to be. I just learned that you have to accept what life gives you and not think you can change it. (brother of a girl with diabetes)

Reference was made earlier to the prevailing belief throughout the locus of control literature that an external locus of control orientation is related to poor adjustment. The present study's finding that living with an ill sibling is associated with an increased belief in chance locus of control (a subcategory of the External dimension of the MHLC scale) challenges the assumption that an internal locus of control is always facilitative. Although no measure of adjustment was included in the present study, one could argue that an increased belief in chance control of health may be realistic and adaptive in the face of uncontrollable illness.

It is important to note here that despite the labeling of the Multidimensional Health Locus of Control Scale as a measure of <u>health</u> locus of control expectancies, close examination of the specific statements within the scale suggests that it is a measure of both health and <u>illness</u> control expectancies, which may not be perfectly inversely related. Statements contained in the Multidimensional Health Locus of Control Scale such as: "When I feel ill I

know it's because I have not been taking care of myself properly", "When I am sick I just have to let nature run its course", and "When I become ill, it's a matter of fate", could be considered reflective of illness rather than health locus of control beliefs. As previous research has shown, the individual's beliefs about control are influenced by whether the event being considered is of a negative or positive nature. It has been found that negative life events are viewed as less controllable than positive events (Nelson & Cohen, 1983) and, more specifically, that the healthy person is given more credit for his/her health than for his/her illness (Lang-Gunn, 1980). Thus, assumptions drawn from results of the Multidimensional Health Locus of Control Scale may be confounded by the fact that subjects are asked to assess both health and illness beliefs.

This confusion between health and illness on the Multidimensional Health Locus of Control Scale relates directly to the initially puzzling findings from the Concept of Illness Task, which measured attributions for illness and health. Experimental subjects had significantly different attributions for the cause of hospitalization/illness as compared to the attributions they made for the prevention of hospitalization/illness. They viewed the cause of hospitalization as due to chance factors but believed that changes in behavior rather than chance factors would influence whether the story child became hospitalized or ill

again. Thus attributions made for health and illness were different. Taken together, these findings suggest that the Multidimensional Health Locus of Control Scale, which is generally considered to be a personality measure, can also be viewed more specifically as a measure of attributional style--the way in which the individual understands the world. Results indicate that despite a lack of differentiation in the measure between health and illness beliefs, the experience of living with an ill sibling affects beliefs about controllability of health and illness.

Perceptions of Vulnerability to Illness. The introduction to this thesis referred to the individuals' need to come to terms with a heightened sense of personal vulnerability when confronted with serious illness. Previous researchers have stated that the experience of having a family member victimized by illness increases individuals' perceptions of their own vulnerability. It is intriguing, therefore, to find in the present study that siblings of chronically ill children, as compared to controls, did not perceive themselves as more vulnerable to illness in the past, nor did they perceive themselves as more vulnerable to illness in the future. Although living with a chronically ill sibling appears to heighten young adults' perceptions of chronic illness in the population, this did not have the effect of increasing their own sense of personal vulnerability. In fact, these subjects tended to view

themselves as much less likely than the average person to become ill with specific chronic disease.

It can be argued that early in the course of childhood illness, the young healthy sibling may indeed experience a heightened sense of vulnerability due to his/her identification with the ill child and his/her consequent anxiety regarding the cause of illness. The illness is most likely to be viewed at this time as particularly acute and severe, as the family struggles to deal with initial diagnosis and treatment. However, as the family and the well sibling become more accustomed to the course of the illness, and reorganize to cope with its demands, the illness may take on a less acute and more chronic nature. As the well sibling grows and continually compares his/her health status with that of the ill sibling, it becomes more apparent that s/he will not succumb to the same illness. It was noted earlier in the literature review that when an individual feels threatened about his/her situation, downward comparisons are often made: the individual will evaluate his/her own outcomes against those of someone doing less well. It is possible then, that in an effort to decrease their perception of vulnerability to illness, these children, and later young adults, utilized this downward comparison process and viewed themselves as especially invulnerable to the unknown chance forces that attacked the

ill child. The descriptive data suggest that this was true for many subjects in this study.

> I do feel like somehow I'm lucky. I feel bad about saying this, but the chances of two people in one family getting the same sickness is pretty low. And, well, he got it and I didn't. (brother of girl with asthma)

The quantitative and descriptive data therefore suggest that young adult siblings view themselves as having "escaped" the illness that afflicted their sibling: their own health is considered confirmation of their personal invulnerability to illness.

Attributions for Health and Illness

The preceding discussion suggests that young adults' perceptions of vulnerability to illness are affected by the reality of living with an ill child over a period of time. Their attributions of illness and health are also likely to be influenced by the fact of living with an ill child and observing uncontrollable remissions and uncontrollable changes in the course of the illness. Results of the present study indicate that despite the latency age siblings' tendency to attribute the cause of illness to the ill child's behavior (Simons, 1982), the young adult no longer maintains this belief. S/he attributes the cause of illness to chance factors rather than to behavior of the victim.

The young adult perceives him/herself as less likely than the average person to become ill. Additionally, s/he

knows that s/he is not likely to become afflicted with chronic childhood disease. It is therefore possible that because s/he does not anticipate a fate similar to that of the ill sibling, the usual motivation for attributions of blame--a need to decrease personal vulnerability--is not aroused. A causal attribution of illness is thus unlikely to be meaningful or important to the young adult sibling of a chronically ill child. Indeed, when the experimental subjects were asked "do you ever or did you ever wonder why this happened to your sibling and not to you?" many subjects appeared puzzled by the question:

> I don't remember why. I still don't wonder. It just is. It's like my other sister has red hair and this sister had diabetes. (brother of girl with diabetes)

> I don't think I ever really thought about it. I guess I used to think that she didn't take care of herself, well, that she was weaker and more susceptible. But after awhile, you just don't think about it anymore, 'cause there's no real reason. (sister of girl with asthma)

> I don't think there's an answer. I don't remember how I answered. I do think about it sometimes now, but all I can say is he made the best of it. (brother of boy with inflammatory bowel disease)

This material suggests that sibling illness is an accepted fact, not a distinct negative event which requires explanation in order to maintain a belief in a just or controllable world.

Family Responses to Childhood Illness: Impact on the Well Sibling

Introduction

In the preceding section, the manner in which healthy siblings' conceptualizations of illness may develop over time was described. It is important to note here that this development is due not only to the fact that the young adult sibling has more experience with sibling illness than his/her latency age counterpart, but that s/he is also confronted with a new set of developmental tasks as she enters adulthood. The subjects in this study were college students who were dealing with the need to develop an identity for themselves as they leave home and separate from family members. The change in siblings of ill children's beliefs about vulnerability to illness and controllability of illness may therefore be related to this normal developmental task of creating a separate identity and resisting pulls toward the home environment.

In addition, the relationship the young adult sibling had with family members, particularly siblings, may impact on the development of their identity as a healthy person entering adulthood. It is interesting to note in this regard, the distinct lack of attention sibling relationships have received in the clinical and research literature. This is especially surprising, given the fact that by age 10, children are spending as much time relating to siblings as

they are to mothers (Black & Sturge, 1979). As Bank and Kahn (1980) have noted, "through sibling relationships, one gets both the sense of being a distinct individual and of constancy through knowing a sibling as a predictable person". These authors argue that the sibling relationship is a "vital key" to each child's knowledge of the self. Researchers, however, have not yet examined how sibling relationships in general affect the development of self identity; and there are no data on how the experience of living with an ill sibling might affect that identity development.

In order to gain a richer understanding of this developing process in siblings of ill children, the descriptive data in the present study will be discussed in relation to the material on latency age children gathered in Simons' (1982) study. Discussion of changes in family dynamics will lead to a description of the well sibling's underlying emotional responses to the events surrounding the illness. The complex interplay of adaptive strategies that the well sibling and the family as a whole utilize to cope with the stress of living with an ill child will then be discussed in terms of both the behavioral coping style of the well sibling and the system-wide coping style of the family.

Altered Family Dynamics and Beliefs

The sibling's reaction to childhood illness can be affected by the changes in family patterns and interactions which occur when a child is diagnosed with a chronic disease. The structure of family life is such that the family as a whole needs to reorganize attitudes, goals, and lifestyles in order to cope with the requirements of caring for a chronically ill child. Simons (1982) found that during diagnosis and exacerbations of the illness, mothers of ill children found it difficult to adequately attend to the emotional needs of their other children, their spouses, or themselves. Dealing with the physical, emotional, and mental demands of caring for an ill child was exhausting for many of the mothers in Simons' (1982) study, resulting in restrictions of family activities and limited ability to respond to the needs of the family.

The impact of childhood illness on the well sibling may in part be determined by the parents' feelings and beliefs about the illness. Descriptive data from Simons' (1982) study indicates that parents often grope for a reason why this misfortune happened to their child. They can feel powerless, knowing that they have limited control over what will happen to their child. The concern regarding selective incidence of illness, referred to earlier in the literature review, is illustrated by the comment of one parent in Simons' (1982) study: "After I asked myself why this was

happening and I learned at least the mechanics of diabetes, I then started asking myself 'Why? Why me? Why my child?'"

There is the suggestion from both Simons' (1982) study and the present study that parents often attribute responsibility for the illness to themselves, believing that they could have done something to prevent or lessen the severity of the illness. The young adults in the present study often recalled struggling with the parental perception that the illness was caused by something other than chance:

> My mother was always a perfectionist and her reaction was to blame herself. That's something that she and I still confront each other on. She says "Oh, its my fault". I sit and say "No it's not". As a child, I guess she wouldn't express that but I must have guessed it and now that I'm older she'll say it. I get angry 'cause that's ridiculous. I just say people are born and that's what life gives you and you have to deal with it and by no means is it you. (young adult sister of boy with diabetes)

This material suggests that the young adult's belief in chance and personal invulnerability may develop in part from a need to defend against sharing the disturbing thought that the parent or sibling has contributed to the development of the illness.

Emotional Impact on the Well Sibling.

Feelings of fear, anxiety, and sadness. Siblings in both Simons' (1982) study and the present study described fears associated with the frightening images they had when the ill child became acutely ill. The recollection of these events was quite vivid, even for young adults who recalled episodes

that happened more than ten years ago. Indeed, one of the most striking findings from the interviews with the subjects in the present study was the disparity between their nonchalant manner of describing the ill sibling's current status ("It's no big deal, we're used to it") and their still vivid and emotional recollections of what it was like to observe the ill child:

> I really remember the first time. I was pretty scared. It was frightening because she couldn't breathe and then the ambulance came and they had to give her oxygen and everyone was running around frantic. I was trying to be cooperative and quiet but I was incredibly scared. (sister of girl with asthma)

> When I was eight, I found out my brother was born without a pulmonary valve. All I remember is that my baby brother was blue and he couldn't breathe. I remember the ambulance lights flashing and that I was scared 'cause no one was really sure what to do with him. (sister of boy with heart disease)

The feeling that at any moment their sibling might become severely ill was extremely frightening to these subjects as children, most likely because they also felt vulnerable to such unknown forces.

A number of children in the Simons (1982) study expressed fears that the ill child would die from the disease. The brother of a girl with lupus was told at age six that his sister was ill and would have good days and bad days. He asked, "Is she going to die? Will I get it? I don't want to die". After seeing a grand mal seizure, he cried, "She's dead, Mummy, I'm scared". At age nine he angrily said to his mother, "I thought she was better and

the lupus was gone". This child was clearly struggling with how to make sense of the very frightening presence of illness while maintaining his own sense of invulnerability.

Siblings in the present study had lived long enough with the ill child to know that s/he was not in imminent danger of dying. In fact, any individuals whose siblings had died were excluded systematically from this study. It is likely, therefore, that the findings in Simons' (1982) study were influenced by the subjects' perceptions of potential death of a sibling, whereas in the present study, any subjects who may have held such fears at one time had learned that the fear of sibling death did not prove true. Thus, since their responses to the quantitative measures would reflect their current feelings about illness, any earlier anxiety regarding the sibling's dying would no longer be relevant to conceptualizations of illness. The words of one young adult reflect this difference:

> I gave him insulin shots when I was younger and alone with him and I watched that he kept to the diet cuz I was so scared that he would die. Now I worry about him and all, but it's nothing like what I imagined when I was little. (sister of boy with diabetes)

As described by the immediately preceding quotation, when placed in the situation of being alone with the ill child, many siblings recollect having felt especially fearful and anxious about potential worsening of the disease. The present study found that young adult siblings

still hold on to intense recollections of being alone with the ill sibling:

> The time she came real close to going into a diabetic coma--that scared me. Not only because it happened but because I was alone in the house with her when it happened. I was little and didn't really know what a diabetic coma was and she was sleeping all day. When I tried to wake her, no answer, so I just figured she was really tired. So there I am watching cartoons and my mother comes running in: "Where's Susan?" and tears down the hall and the ambulance comes and they couldn't get her up or anything because she was starting to go into a coma. I didn't know enough to know what I should have done and I was all alone. (sister of girl with diabetes)

Feelings of sadness and concern on the part of the well sibling when the child was in the hospital were also common. The young adult siblings often described scenes of sitting at home, crying and praying while the child was in the hospital. The sister of a girl with Hodgkin's disease in Simons' (1982) study described these sad moments during the illness:

> Sometimes when I'm home and they're there [at the hospital] I turn off the TV and I think about [my sister]. I ask myself all these questions that nobody can answer, like what's going to happen next?

Feelings of anger, resentment, and guilt. When one child's needs are met at the expense of another's, feelings of resentment and hostility are unavoidable. During the interviews with the latency age children in Simons' (1982) study, many expressed a great deal of hostility toward the ill child for the demands he or she made on the parent. They viewed the time the parent spent with the ill child as

"stolen" from them. One young adult in the present study, who was generally rather casual regarding the effect of sibling illness on his life, recalled with intense emotion an incident when his sister was in the hospital on the day of his birthday. "I'll never forget it because my father never wished me a happy birthday and wouldn't wake up when everyone gave me presents". The question one boy in the Simons (1982) study posed to his sister with lupus, "Aren't you feeling all right yet? I thought your lupus was going away", reflects the child's underlying resentment of the neediness of the ill sibling.

A number of the siblings expressed anger not only at the ill child but also at the parents for complying with the ill child's demands. When asked what she had been told about diabetes by her parents, a young girl in Simons' (1982) study replied: "They told me that my brother has to have special care now. But that was a long time ago and you know they really don't have to give so much special care like they do". This little girl often cried when her mother left the house for diabetes fundraising activities, demanding that she "stop doing that stuff". The young adults in the present study expressed both anger and disappointment at the parents for "giving in" to the ill sibling:

> It really changed my mother and it's too bad. I can see now that she didn't see what was happening, how over-involved she got and how this affected her. Like, she had a job before all this

> and she insisted on staying home with Joey even though he didn't need it. And he got spoiled by that attention that we didn't get and now he expects it all the time. (sister of boy with diabetes)

> I get mad inside most when she was getting a lot of attention. You have to be patient though. When your sister is sick you have bad feelings about the illness but not her. I mean, your parents expect you to understand why they're giving her all the attention but it's hard. I guess it's more hate toward the illness not the sister. Well, just jealousy, not really hate. (sister of girl with asthma)

It is clear from these statements that feelings of hostility and resentment are naturally exacerbated by family response to the ill child. As the quote above suggests, it may be that a sense of guilt limits the acknowledgement of such feelings. Sourkes (1980) has noted that feelings of guilt in well siblings are multifaceted. The well sibling may feel guilty for causing the child's illness and/or escaping the illness. The young adult sister of a girl with asthma related how she often said, "Please God, let her be all right and me be sick. And then I'd say--wait a minute, do I really want this?" According to Sourkes (1980), "acknowledgement of their relief at being healthy only triggers the guilt more intensely" (p. 59).

The interview data indicates that many siblings feel anxious and guilty about the unacceptable (but understandable) angry and hostile feelings they hold toward the ill siblings and toward their parents. Often cut off from reassurance and emotional support, they secretly hold on to feelings of intense guilt both for the anger they have felt

and for fantasies of having hurt the ill child by some thought or behavior. The brother of a girl with muscular dystrophy in Simons' study said, "I used to make fun of her because she would trip and I didn't know what it was. It makes me feel bad". When asked what the experimenter should tell other children who have a sister with diabetes, an eleven year old girl in Simons' study responded:

> Tell them not to feel mad at yourself because you didn't really cause it. Because I felt mad at myself for awhile. I thought for two years that I had been bugging her too much and that that made her eat more sugar.

Even young adults seem to harbor feelings of guilt regarding their early feelings toward the ill sibling. The young man who so emotionally described his father missing a birthday celebration when his sibling was ill later told the interviewer: "I shouldn't have felt that way. I wish I didn't think about myself so much. And I shouldn't have complained all the time about doing the dishes. It was 'me, me, me,' and I feel bad".

The subtle, complicated, and ambivalent feelings that arise in a child who must accommodate to the needs of a family with a chronically ill child are clearly illustrated in the words of an eleven year old with a sister with diabetes (Simons, 1982). In describing her anger at the restrictions imposed on the family by the diabetes, she said:

> Like when we can't go out to dinner. I'll go upstairs and watch TV. Mostly I feel mad at

> myself. Well not really myself but things that got her diabetes. Like I don't, it's not really her fault. My mother and father, you know, it's not their fault either. So I get mad at no one. I just get mad at myself.
> [Experimenter]: You get mad at yourself?
> Yuh--cuz like I should know better not to get upset.

Siblings seem to struggle to understand the causes for illness at the same time that they battle to control the resentful feelings they have about the sibling illness. Unable to express anger directly toward the sibling or parents, they turn these feelings on themselves.

Bank and Kahn (1981) have argued that aggression between siblings, even when painful, represents "contact, warmth, another presence". However, data from both Simons' (1982) study and the present study indicate that well siblings must often deny their competitive feelings because of the fear that they might hurt the ill sibling:

> I used to punch him when I was mad but I now I can't because he's got a tube in his brain to his stomach and he could get hurt real bad. (boy with brother with brain tumor, Simons, 1982)

> When I used to play baseball I really wanted to strike him out, like when I was pitching. But then I'd have to sit back and think, "What if I were Bob?" He's got epilepsy and he's lucky if he hits it right. And I knew I had to be careful to throw it right too so he didn't get hit with the ball either. (young adult with brother with epilepsy)

Thus, although healthy siblings will naturally feel anger at both the ill child and the parents, there are strong forces at work which are conducive to the control of such feelings. As the next section describes, the inability to discharge or resolve angry feelings directly may lead

these siblings to adopt particular behavioral styles in an attempt to cope with their conflicting feelings.

Behavioral Coping Style: The Caregiving Role

The conceptual coping styles adopting by these children and young adults have been discussed in regard to the results of the quantitative data examining conceptualizations of illness and perceived personal vulnerability. Material from interviews with siblings suggests that similar issues of coping styles can be examined from a behavioral perspective of role. Both the present study and Simons' (1982) found that acting as a caregiver to ill siblings was a predominant response for healthy siblings, perhaps having implications for later decisions made in young adulthood.

The need "to be good and obey the rules" as revealed in Simons' (1982) study seemed to influence many of the siblings' behavioral adaptations to the illness. A number of the well siblings took it on themselves to watch over the ill child and attend to his/her medical and emotional needs. For example, siblings of children with diabetes often denied themselves sweet food, awakened and prepared their brother or sister for insulin shots, and monitored the ill child's food intake. This caregiving behavior often continued into young adulthood. Subjects in the present study had increasingly assumed responsibility for patient care, and were often involved in taking the ill sibling to clinics, administering insulin shots, and meeting with

medical staff. One young adult spoke of "standing over my sister to make sure she took her medication even if she screamed at me." The young adult sister of a boy with diabetes recalled receiving a phone call from her brother to say he had consumed too much alcohol:

> I remember going over there--he was so bad, I was afraid he'd go into a coma. So I carried him home and made him get sick and gave him eight shots from ten in the night to six in the morning.

Many young adult siblings demonstrated remarkable sensitivity to the emotional needs of the ill sibling. The brother of a girl with muscular dystrophy describes his relationship with his sister as particularly close, and views himself as her "pressure valve. Sometimes I get her going on purpose so she can yell and scream and get those feelings of frustration out."

The well siblings' protection of the ill child from outsiders' negative comments was often quite striking, as revealed both in the interviews with the latency age children and with the young adults. Well siblings often defended the ill child from the teasing of peers, and "even children who were indifferent within became champions without" (Burton, 1975, p. 194). Indeed, even the young adults in the study who were able to describe themselves as not particularly close to the ill sibling related stories of how they defended the ill sibling from outsiders' questions and curiosity. This defense of the sibling could also be

considered a defense of themselves and their own negative feelings about having a "deviant" sibling.

It is important to note here that this manner of caring for the ill sibling was not a consistent response for well siblings. Even those who described themselves as the closest sibling to the ill child described periods of feeling emotionally detached and separated from the ill child. A pattern of strategic withdrawal, particularly during adolescence, emerged in these interviews. It appeared that the need to separate one's own identity from that of the ill sibling helped to maintain the integrity of adolescent development and enabled many of the well siblings to become supportive and empathic at a late date.

For many siblings, intellectualization in the caregiving role seemed to serve an adaptive defense. They sought information about the illness at the library, wrote papers in school about what it was like to be the brother or sister of an ill sibling, and attended support group meetings with their ill siblings. An identification with the medical staff and a desire to care for others led many of the children in Simons' (1982) study to state that when they grew up, they wanted to be doctors, nurses, or priests. Having a sibling for whom they could care allowed these children to feel successful and in control. It was intriguing to find, therefore, that the young adult siblings of ill children in the present study were significantly more

likely than the comparison group of siblings to choose majors directed toward the "helping professions". Many of these subjects stated that the experience of caring for an ill child increased their tolerance for other people and interest in humanitarian concerns; they directly related the sibling illness to their decision to pursue helping professions.

As Simons (1982) argued in the discussion of latency age siblings of chronically ill children, the adoption of nurturant caretaking behavior may serve a defensive but adaptive function of differentiating the well child from the ill child. In caring for the sibling, the well sibling reassures him or herself that he or she is not like the ill child. Striving for success in domains which emphasize the physical difference between themselves and their ill siblings may be another way of developing this self-identity.

The descriptive data suggests, however, that the caregiving role, while adaptive, may carry certain risks of its own. In adopting the caregiving role, the children may be responding to their parents' needs to be reassured of a difference between their ill and well children. Well siblings often seemed to feel a special burden to excel, sensing the parents' need for them not to become ill. In a desire to compensate for the inability of the ill child, many of these siblings worked fervently to achieve all their

parents' expectations. As one young adult sibling recalled: "My mother's reaction was to blame herself. . . . I told her to look at the rest of us kids. See, we show there's nothing to show you're a bad parent".

In this attempt to protect the parents against feelings of failure, the well siblings may adopt an overparentified role with potentially problematic consequences for their later development. The following are the words of a young adult sibling who became caregiver to her brother with cancer, but now struggles with the effect of that experience on her feelings about leaving home:

> He's like my own child. I raised him, took care of him. When he was two, my mother had to do her thing and go to work. I resented it. He was like my own kid. Now I'm at school and my mother takes care of him but I think she's overprotective. [Later in the interview]: It's hard leaving home now. I guess it would have been different if he wasn't sick. But we got closer and I took care of him. Guess that's why they have such a strong hold on me now. Why it's hard to break away. If I leave, I'll feel like I'm abandoning them.

Family Communication: System-Wide Coping Styles

Thus far we have considered both cognitive and behavioral coping styles the healthy sibling of an ill child may adopt in an effort to adapt to the stress of living with chronic illness. The family's communication style also appears to be an important variable in alleviating stresses experienced by family members when faced with childhood illness and may influence well sibling's beliefs and behavior. Two generally distinct communication styles:

closed and open, seemed to distinguish families in both the present study and in Simons' (1982) study.

The following statements reflect the isolation experienced by family members in the closed style, when the child's illness is considered a family secret:

> I still don't know what it is. When I was four I heard my mother talking on the phone to the doctor and I heard her say Marie had cystic fibrosis and I got scared. I tried to look it up in the encyclopedia but I couldn't read too good then. . . . I know she gets banged on but she won't let me go down there so I don't really get it. . . . We don't talk about tit at home. . . . She doesn't want anyone to know but I don't know how she can hide it without it showing. . . . the first thing I'd tell someone if their sister had cf is don't tell your friends cuz they'll start blabbing it and they'll tell their mothers and their mothers will tell your mother and she'll kill you cuz she said not to tell anybody and she won't have any friends left. (latency age brother of girl with cystic fibrosis, Simons, 1982)

> Actually, I don't really like talking about it. I mean, no one in our family ever did and I thought it bothered Kathy to have me ask questions so I never did. I never even asked my father cuz he would have gotten mad at me. I remember thinking she was a hypochondriac cuz she'd have these terrible headaches and she'd be screaming. Later we find out it's diabetes which made me feel kind of bad for a long time.
> I guess I sort of put it out of my mind. I just sort of followed my parents. Like she doesn't have diabetes, it's just something that will pass, like a cold. Just sort of put out of your head. Not sure I should've done that cuz she's always going to have it and it's not going away. But, I don't know, I just try not to think of it and no one in the family will ever talk about it. I don't even think any of our relatives really know. (young adult sister of girl with diabetes)

Several young adults in the present study recalled feeling lonely and confused as they struggled to understand

what was happening to their brother or sister. The young adult sibling quoted above stated that she didn't ask questions because she didn't want to "bother" her sister or brother. There is the suggestion in the descriptive data that siblings' silences may be due to their attempts to protect family members, sensing parental unwillingness to openly deal with the problem. As Share (1972) found in her study of communication in families of the terminally ill, "in an effort to avoid loss of contact and maintain approval of significant adults, [the child] quickly learns to keep his thoughts to himself".

It is likely that if the family's communication style does not allow for open discussion of the illness and feelings about the illness, the well siblings' fantasies and fears about the illness are left unaddressed. Gogan and Slavin (1981) in their investigation of sibling response to illness (as part of a larger study on the psychosocial consequences of surviving childhood cancer) found that

> the family that openly and actively seeks and discusses information and which shares feelings about the illness is less likely to produce such side effects as guilt ridden siblings. . . . Closed communication systems in families may contribute to the development of behavioral and emotional problems among the cancer patient's siblings. Many of the siblings' problems could apparently have been ameliorated by providing direct factual information at the time of diagnosis and during treatment. (Gogan & Slavin, 1981, pp. 109-110)

Siblings who do not have clear information about the illness cannot use the often adaptive defense of intellectualization

and caregiving described earlier. And, when each family member believes that he or she is alone with his/her hostile or fearful feelings, everyone is caught in a "web of silence" (Turk, 1964). Share (1982) argues that a vicious style ensues in these families with closed communication styles:

> The adult, as a result of lack of meaningful communication with his child, becomes increasingly unable to accurately perceive, assess, and respond to the child's inner experience. The child, in turn, respond to the adult's apparent "unawareness" with further withdrawal, accompanied by feelings of loneliness and increased isolation. (Share, 1972, p. 198)

In the words of a young adult brother of a boy with epilepsy,

> I guess when I look back I remember feeling "why", "how come", "it's not fair". And their explanation was, "Just accept it; that's the way it is and don't bug me". I think back of how they handled it and I think they should have explained it more when we were children. Because I was in the dark a lot and never really knew what he had. And watching a brother with epilepsy is scary.

Although in some families, preexisting communication patterns may have originally reflected a more closed communication style, data from the interviews with young adults suggests that as families reorganize to cope with illness, they may change the manner of communicating with each other. Many of the young adults said that in retrospect, the experience brought the family closer together:

> It was always kind of like everybody living in their own worlds, separated, not close at all. It brought us closer by focussing our attention on

> him and now it's not so much our own little worlds of going out and not caring about anyone else. (sister of boy with asthma)

> At first it was a touchy subject. Everyone put it in the back of your mind and went about your daily routine. When I was younger it was just like, you went to school and your sister, she's sick but she'll be okay and don't worry about it and let's not talk about it. Then as time went on it made it to the dinner table and now it's nothing. We talk about it and sometimes get upset and sometimes just laugh at the funny parts of it all. (brother of girl with diabetes)

In families with the open communication style, parents took the time to sit down and explain to the well sibling the facts about the illness: the rigid schedule for the child with diabetes, the special needs of the child with asthma, the reactions of the child with seizures, the side effects of chemotherapy for the child with leukemia. As the following comment by a young adult in the present study suggests, this openness about the illness also helped the well sibling maintain a trust that the parents would be open with them as well.

> When I was sick myself, I used to wonder if something was really wrong with me and everyone wasn't telling me. But then I thought, since we all know something is wrong with Joey and he's eight and he knows, they'd tell me. That did make me feel more secure that my parents would be open about other things. (sister of boy with heart disease)

In the open communication style, parents seemed to be able to acknowledge and accept the strong feelings elicited by the illness, as these quotes from Simons' (1982) study illustrate:

> We got the biopsy results on Tuesday . . . and on Thursday my husband cried. After that I knew it was going to be all right. Until he cried, I was very concerned about him and about us. (mother of girl with Hodgkins' disease)

> I remember I talked to the nurse and she asked me what scared me the most. I said that somebody at school might say to Katie, "Your sister has cancer and she's going t die." And the nurse said, "You'll have to say those words, you'll have to tell her the possibility, while giving her hope." And I did. We cried, but she already knew at some level and she needed to have it talked about. (mother of girl with Hodgkins's disease)

The parents' clear acknowledgement of feelings of anger, fear, and sadness seemed to be communicated to their offspring in a way that allowed the well siblings to accept similar feelings in themselves. When a young adult in the present study was asked what she would tell a youngster about coping with sibling illness, she responded:

> . . . Well, remember it's your brother and you'll always care. But you're going to be real frustrated at times. Even you parents do. You're going to slip--that's important when you're telling a kid how to cope with it. Don't say you can deal with it all the time--no one can. You just stick together as a family and talk and work it out. (sister of boy with epilepsy)

The effect of open communication on both the ill and well siblings' attitudes toward the illness is beautifully illustrated by the following comments by the mother of a child with Hodgkins' disease in Simons' (1982) study:

> What I'd tell other parents is you can't lie to your kids. You tell the truth to different age levels, but there's no point in pretending that it's not serious or that you're not scared, because they know you are . . . [My daughter] said to me at one point, I wonder how many kinds died because of the way things used to be, that they

couldn't talk to their parents and therefore the parents couldn't spend the time encouraging them.

Methodological Issues and Implications of Findings for Future Research

Methodological Considerations

As was discussed in Chapter One, most investigations of sibling responses to childhood illness have produced inconclusive or conflicting results. This state of affairs reflects in part the methodological limitations of previous studies, most of which relied on subjective measures and did not utilize control groups for comparisons. The present study represents an attempt to minimize these methodological limitations. The complicated attributions and feelings of vulnerability in siblings of ill children were operationalized in this study by several different methods of assessment, and were explored by making use of a control group for comparison. Because particular characteristics of the ill child and sibling may mediate the effects of sibling illness on the well sibling, a number of potentially influential factors were systematically matched in the present study: socioeconomic status, age of well sibling, gender of well sibling and of ill sibling, family size, and birth order. Standardized measures were also included in this research, allowing comparisons with research using these same measures with other samples.

However, there are several methodological limitations in the present study. Four hundred and eleven young adults indicated they were interested in participating in the study; however, only 32 individuals fit the selection criteria for the experimental group and 5 of these potential 32 experimental subjects could not be tested. The resulting number of 27 subjects in the experimental group and 27 subjects in the control group is relatively small, which may limit the conclusions that can be drawn from the study's results.

Although subject recruitment and selection procedures were designed to match subjects on a variety of variables and to select subjects representative of the general population of siblings of well and chronically ill children, subjects in this study were self selected. It is not known what factors influenced subjects' motivation to participate in the study and whether potential subjects who chose not to participate in the study did so for reasons which could affect the findings. Additionally, the subjects in this study were all college students, the majority of whom were enrolled in psychology courses. Thus, generalizations for the population of siblings at large are constrained by the limits of research on this selected group.

The choice of measures in this study also imposed limits on the conclusions that can be drawn from the results. The questions on most of the measures were face

valid ones, and it is possible that their obvious nature evoked conscious appraisal of the researcher's intended purpose. It is not known if this significantly affected subjects' responses to the quantitative measures. Discussion of the findings of the descriptive measures are also constrained by the limitations inherent in retrospective, descriptive data.

Finally, while much of the interpretation of the results relies on comparisons between subjects in the Simons (1982) and the present study, it cannot be assumed that the two groups are in fact comparable. Although both groups were drawn from the same geographic area and have had similar socioeconomic backgrounds, the type of sibling illness in the two groups was not matched. It is possible, therefore, that there were significant differences between the two groups that render untenable conclusions based on comparing the latency age siblings of Simons' (1982) study and the young adult siblings in the present study. And, in fact, one specific difference, namely present concern over the sibling's death, has already been mentioned. Comparisons between the two studies are at the very least heuristic, however. Clearly, a longitudinal design, following the same subjects through their life spans would be the ideal way of examining the developmental aspects inherent in the sibling relationship and, specifically, how

the impact of childhood illness on the healthy sibling changes over time.

Summary and Implications for Future Research and Interventions

The present study examined the effects of chronic childhood illness on healthy siblings. The results indicated that living with an ill sibling during childhood has a powerful impact on young adults' conceptualizations of illness and goals for the future. In contrast to peers who have not lived with an ill sibling, these young adults maintain a stronger belief in chance rather than internal behavior as controlling health and illness. In addition, the experience of caring for an ill child leads many to choose majors in college which will prepare them for the helping professions.

Descriptive data in this study revealed the specific pressures and burdens that chronic illness places on family members. A complex interplay of adaptive strategies utilized by the well sibling and the family as a whole was described. As a behavioral coping style, the well sibling's caregiving role seems to have implications for later development in terms of leaving home and creating a separate identity. As a system-wide coping style, the family's communication patterns seemed to influence the well sibling's conceptualizations of illness and ability to cope with sibling illness.

A comparison of the results of the present study of young adult siblings with the results of Simons' (1982) study of latency age siblings suggests that the impact of childhood illness upon well siblings reflects both continuity and change at different stages in the well sibling's development. It was argued that early in the course of the illness, well siblings may experience a heightened sense of personal vulnerability and therefore make attributions based on a need to regain a sense of personal invulnerability. As the family becomes more accustomed to the course of the illness, reorganizing to cope with its demands, the illness is perceived as less acute and more chronic in nature. At the same time, the well sibling is struggling to develop an identity for him/herself. It was suggested that well siblings' perceptions of vulnerability and beliefs about illness develop and change in relation to these developmental processes in the family and within themselves. As young adults, they view themselves as less vulnerable to illness than the average person, and they no longer feel pressured to make attributions for illness based on a need to believe in a just or controllable world.

These results have implications both for future research and for the planning of interventions. The focus of this study was on the effect of childhood illness upon the well sibling. However, it is likely that the ill

child's adaptation to illness is strongly influenced by the beliefs and behavior of the well sibling as revealed in this study. Therefore, further research could examine the bidirectionality of effects in sibling relationships involving ill children as they develop over time.

Correlations between the variables of family communication style and the variables of sibling conceptualization of illness could also be an important direction for future research. An understanding of how family communication patterns might influence the well sibling's beliefs about illness could be helpful in planning intervention strategies for these families. Such an approach might attempt to delineate activities such as family rituals, which emphasize for families of ill children real and symbolic control within the larger context of shared vulnerability to fate.

Prior to the present study, there were no established or agreed-upon normative models for assessing adaptive response to the kind of stress represented by sibling illness. The results of the present study and Simons' (1982) study provide new information on the normal developmental process of sibling response to illness. Clinicians and researchers could potentially utilize this information in assessing whether a given sibling's beliefs and behavior in response to childhood illness are typical of most siblings in this situation. Such a comparison may

allow clinicians and researchers to better assess when certain coping styles are not adaptive, and when, therefore, intervention might be useful. Finally, the combined studies' intimations suggesting developmental shifts in well siblings' conceptualizations of illness over time should be taken into account by researchers and clinicians when evaluating whether certain interventions into the lives of these siblings have indeed been effective.

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APPENDICES

APPENDIX A

Initial Screening and Information Form

SIBLING RESEARCH PROJECT

INITIAL SCREENING AND INFORMATION SHEET

The Sibling Research Project is an investigation of the effects of chronic, serious childhood illness on healthy siblings. In this section of the study, we are interested in exploring how the stress of living with a chronically ill child has affected the lives of healthy brothers and sisters who are now young adults.

In order to make the research design methodologically sound, we would like to test college students who grew up with an ill child in the home, and compare their responses with college students who did not grow up with an ill child in the home. Therefore, if you have a brother or sister, you are eligible for the study.

Your participation in the study would involve filling out a form regarding your family background, and answering questionnaires designed to determine the way in which you view certain health related issues. Your answers will be kept completely confidential. The procedure should take less than one hour, for which you will receive one experimental credit.

Those individuals who have grown up with an ill brother or sister are invited to participate in a second part of the study as well. This would involve speaking with a doctoral student about your thoughts and experiences. If you would like to participate in the interview part of the study, you will be given an additional experimental credit for that hour. Again, your responses will be kept confidential.

If you are interested in participating in the project, and you have lived with either an ill sibling or a well sibling, please fill out the attached information sheet.

Lee Ann Simons, M.S.
Tobin 620

545-1559

PLEASE CIRCLE OR FILL IN THE CORRECT INFORMATION

Name: _____

Phone #: _____ Best Time to Call: _____

Class: Fresh Soph Jnr Snr Other: _____

Sex: Male Female

Age: _____

Residence: Parent's Home School Other: _____

Marital Status: Single Married Separated Divorced

Please list ages of brothers and/or sisters:

Brothers: _____

Sisters: _____

Have any of your brothers or sisters been under medical care for a chronic illness?* YES NO

IF YES: Was this a brother or sister? _____

Was this an older or-younger sibling? _____

Is he or she still living? _____

What was the illness? _____

How long did you live with this brother/sister? _____ (years)

Have you or your parents been under medical care for a chronic illness? YES NO

IF YES: Please describe: _____

_____

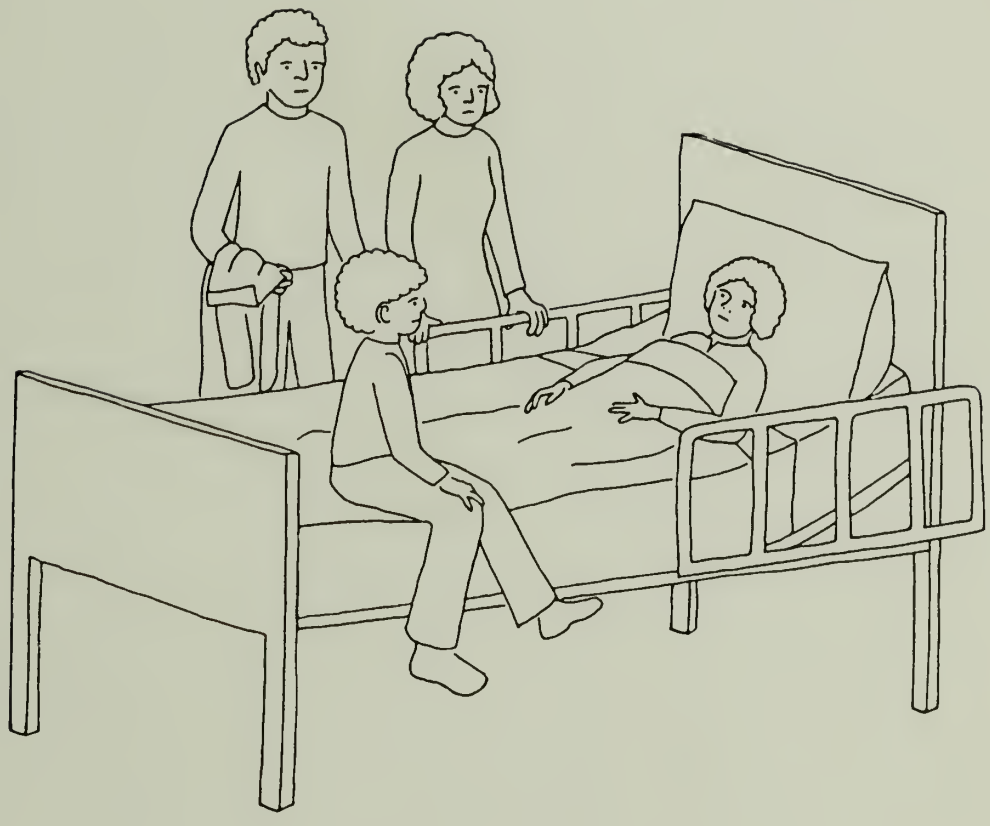
_____

*Chronic illness could be diabetes, cystic fibrosis, muscular dystrophy, Hodgkin's disease, lupus erythemotosis, severe asthma, seizures (without mental retardation), or any other long term physical condition.

----------THANK YOU VERY MUCH FOR YOUR HELP----------

APPENDIX B

Concept of Illness Task



SUBJECT # _____

PLEASE USE YOUR IMAGINATION AND MAKE UP A STORY ABOUT WHY THIS PERSON IS IN THE HOSPITAL BED. THEN, PLEASE ANSWER THE FOLLOWING QUESTIONS:

1. Why is this person in the hospital? What is wrong with him/her? Please be specific.

2. How did this person get sick or hurt? What factors contributed to his/her hospitalization?

3. What was this person doing when he/she got sick or hurt?

4. Will he/she improve? If so, how will that happen? What factors will contribute to his/her improvement?

5. How likely is it that this person will need to be hospitalized again?

6. How can he/she keep from getting hospitalized again? How can he/she stay healthy?

(PLEASE USE THE OTHER SIDE IF MORE SPACE IS NEEDED)

APPENDIX C

Multidimensional Health Locus of Control Scale

Form A

Subject # _____

MHLC

This is a questionnaire designed to determine the way in which different people view certain important health-related issues. Each item is a belief statement with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you disagree or agree with the statement. The more strongly you agree with a statement, then the higher will be the number you circle. The more strongly you disagree with a statement, then the lower will be the number you circle. Please make sure that you answer every item and that you circle only one number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

Please answer these items carefully, but do not spend too much time on any one item. As much as you can, try to respond to each item independently. When making your choice, do not be influenced by your previous choices. It is important that you respond according to your actual beliefs and not according to how you feel you should believe or how you think we want you to believe.

	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
1. If I get sick, it is my own behavior which determines how soon I get well again.	1	2	3	4	5	6
2. No matter what I do, if I am going to get sick, I will get sick.	1	2	3	4	5	6
3. Having regular contact with my physician is the best way for me to avoid illness.	1	2	3	4	5	6
4. Most things that affect my health happen to me by accident.	1	2	3	4	5	6
5. Whenever I don't feel well, I should consult a medically trained professional.	1	2	3	4	5	6
6. I am in control of my health.	1	2	3	4	5	6
7. My family has a lot to do with my becoming sick or staying healthy.	1	2	3	4	5	6
8. When I get sick I am to blame.	1	2	3	4	5	6

Form A

	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
9. Luck plays a big part in determining how soon I will recover from an illness.	1	2	3	4	5	6
10. Health professionals control my health.	1	2	3	4	5	6
11. My good health is largely a matter of good fortune.	1	2	3	4	5	6
12. The main thing which affects my health is what I myself do.	1	2	3	4	5	6
13. If I take care of myself, I can avoid illness.	1	2	3	4	5	6
14. When I recover from an illness, it's usually because other people (for example, doctors, nurses, family, friends) have been taking good care of me.	1	2	3	4	5	6
15. No matter what I do, I'm likely to get sick.	1	2	3	4	5	6
16. If it's mesnt to be, I will stay healthy.	1	2	3	4	5	6
17. If I take the right actions, I can stay healthy.	1	2	3	4	5	6
18. Regsrding my health, I can only do what my doctor tells me to do.	1	2	3	4	5	6

Scoring Instructions MHLC

The score on each subscale is the sum of the values circled for each item in that subscale.

Internal Items:	1, 6, 8, 12, 13, 17
Chance Items:	2, 4, 9, 11, 15, 16
Powerful Others Items:	3, 5, 7, 10, 14, 18

APPENDIX D

Vulnerability to Illness Questionnaire

SUBJECT # _____

PLEASE CIRCLE YOUR BEST GUESS OF THE CORRECT NUMBER:

DURING THE LAST SIX MONTHS, HOW MANY TIMES DID YOU

CATCH A COLD?

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

HAVE AN ACCIDENT OR PHYSICAL INJURY?

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

HAVE A "TENSION" HEADACHE?

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

HAVE A "STOMACH FLU"?

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

HAVE A FEVER?

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

MISS CLASSES BECAUSE YOU WERE ILL?

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

SEEK MEDICAL TREATMENT AT HEALTH SERVICES?

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

SUBJECT # _____

PLEASE CIRCLE YOUR BEST GUESS OF THE CORRECT NUMBER:

DURING THE NEXT SIX MONTHS, HOW MANY TIMES DO YOU THINK YOU WILL

CATCH A COLD?

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

HAVE AN ACCIDENT OR PHYSICAL INJURY?

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

HAVE A "TENSION" HEADACHE

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

HAVE A "STOMACH FLU"?

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

HAVE A FEVER?

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

MISS CLASSES BECAUSE YOU ARE ILL?

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

SEEK MEDICAL TREATMENT AT HEALTH SERVICES?

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

APPENDIX E

Likelihood of Illness Scale

Subject # _____

LI SCALE - 1

How likely do you think it is that you will develop the illness or condition listed below at some point in your life?

	Extremely Unlikely	Moderately Unlikely	Slightly Unlikely	Slightly Likely	Moderately Likely	Extremely Likely
1. food poisoning	1	2	3	4	5	6
2. diabetes	1	2	3	4	5	6
3. coronary heart disease	1	2	3	4	5	6
4. kidney infection	1	2	3	4	5	6
5. cancer	1	2	3	4	5	6
6. pneumonia	1	2	3	4	5	6

Subject # ___

LI SCALE - 2

How likely do you think it is that the average person in this country will develop the illness or condition listed below at some point in his/her life?

		Extremely Unlikely	Moderately Unlikely	Slightly Unlikely	Slightly Likely	Moderately Likely	Extremely Likely
1.	food poisoning	1	2	3	4	5	6
2.	diabetes	1	2	3	4	5	6
3.	coronary heart disease	1	2	3	4	5	6
4.	kidney infection	1	2	3	4	5	6
5.	cancer	1	2	3	4	5	6
6.	pneumonia	1	2	3	4	5	6

APPENDIX F

Family Background Form

SUBJECT # _____

FAMILY BACKGROUND FORM

1. Please list the individuals who lived in your home when you were growing up, in terms of their relationship to you (mother, brother, uncle, etc.) and their present ages:

RELATIONSHIP	AGE	IS THIS PERSON CURRENTLY LIVING IN YOUR FAMILY'S HOME? yes/no
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

2. Are both your parents living? YES NO

   What was their marital status during the majority of your childhood? (Circle one)

   married separated divorced

3. Do any of your family members (brothers, sisters, parents, aunts, uncles) live near you? YES NO

   IF YES: Who? _____ _____

   How close do they live to you? _____

   How often do you see them? _____

   _____

4. Have any of your family members been helpful to you in your concerns about college life? YES NO

   IF YES: Please describe who they are and how they have been helpful:

   _____

   _____

   _____

   _____

   _____

5. Please indicate how many of years of schooling your mother completed: (circle one)

Junior High (10 years or less)
High School (12 years or less)
Some College (13-15 years)
College Graduate (16 years)
Graduate Work Beyond College

6. Please indicate your family's income (approximate) last year:

0 - $5,000
$5,001 - $10,000
$10,001 - $15,000
$15,001 - $20,000
$20,001 - $25,000
Over $25,000

7. Did you have an imaginary friend when you were a child? If so, please describe the experience, including your age, and how long it lasted.

_____

_____

_____

_____

_____

_____

8. What is your major in college, or what do you plan to major in? Any particular reason why you have chosen that area?

_____

_____

_____

_____

_____

IF YOU DID NOT GROW UP WITH AN ILL BROTHER OR SISTER IN THE HOME, THIS IS THE END OF THE QUESTIONNAIRE. THANK YOU VERY MUCH.

IF YOU DID GROW UP WITH AN ILL BROTHER OR SISTER IN THE HOME, PLEASE ANSWER THE FOLLOWING QUESTIONS AS BEST YOU CAN. THANK YOU.

9. What was the age of the ill child when your family first suspected that he or she was ill? _____

10. How old were you? _____

11. Were you involved in any aspect of the medical care for your ill sibling? (Circle one)

YES

NO

IF YES: Please describe: _____

_____

_____

_____

_____

12. Do you think the family's social activities were restricted due to the illness? (Circle one)

YES

NO

IF YES: Please describe: _____

_____

_____

_____

_____

_____

13. What do you remember being told about the illness over time?

Please indicate your age at different times, what you remember being told, and what you remember thinking or feeling:

Age: _____ What you were told: _____

Your reaction: _____

Age: _____ What you were told: _____

Your reaction: _____

Age: _____ What you were told: _____

Your reaction: _____

14. What kinds of questions, if any, did you used to ask your parent(s) about the illness? How often would you ask them about the illness or your sibling?

_____

_____

_____

_____

_____

_____

15. Was there anything you knew about the illness but your ill brother/sister did not? If yes, please describe.

_____

_____

_____

16. Were you or have you been involved in a support group for siblings of ill children? (circle one)

YES

NO

IF YES: Please describe, including what may have been especially helpful about the experience: _____

_____

_____

_____

_____

THANK YOU VERY MUCH FOR TAKING THE TIME TO FILL OUT THIS QUESTIONNAIRE.

APPENDIX G

Clinical Interview Questions

OUTLINE OF QUESTIONS FOR INTERVIEW SECTION OF STUDY

Anything want to add to questionnaire answers.

How often do you see ill sib now.

In what ways are you alike, different.

Do you still have questions about the illness. Have you looked for information on your own.

What do you remember about the first time you found out he/she was ill.

Who talked to you about the illness.

How do you think this has affected you, changed you. (How might things be different if sib wasn't sick.)

- in terms of relationships within family, outside family.

What did you do when you felt sad or angry about the illness. What might make you feel that way.

What do you remember thinking about when you got sick. What do you think about now.

Did you tell your friends about the illness at the time. How about now.

Did you ever ask yourself: why my brother/sister. Why not me. How did you answer that then. How about now.

Can you think of some positive effects of living with a chronically ill sibling.

Did your family talk about the illness as a group. Or did particular members want to talk but others not.

What was particularly confusing to you about the illness. Upsetting. Did you communicate with anyone about that.

Any advice you would give a youngster just finding out that his or her sibling has a chronic illness.

APPENDIX H

Informed Consent Form

INFORMED CONSENT FORM

I understand that my participation in this study will consist of my filling out a form regarding my family background, and answering questionnaires designed to determine the way in which I view certain health related issues. I understand that I will receive one experimental credit for every hour or portion of an hour that I participate. I also understand that I may refuse to answer any question, and that I may leave at any time I wish before completing my participation in this study. I understand that if I do decide to leave I will not be penalized in any way.

I understand that at the end of my participation I may ask any questions about the procedures of the experimenter and that at that time I will be given a written explanation of the study.

I understand that all the materials I provide in this study will be kept strictly confidential, and that any written or recorded material will be identified with a number instead of my name.

_____ _____

Signature of Participant Date